DOCUMENT RESUME

ED 084 735 EC 060 529

TITLE	Kansas Citizens Plan Comprehensive Mental Retardation Services. Summary and Recommendations.
INSTITUTION	Kansas State Dept. of Social Welfare, Topeka. Div. of Institutional Management.
SPONS AGENCY	Public Health Service (DHEW), Washington, D.C.
PUB DATE	Aug 66
NOTE	83p.
EDRS PRICE	MF-$0.65 HC-$3.29
DESCRIPTORS	Educational Needs; *Exceptional Child Education; Mentally Handicapped; *Mental Retardation; *Program Planning; State Legislation; *State Programs; State Surveys
IDENTIFIERS	*Kansas

ABSTRACT

Summarized are the recommendations and findings of 1 1/2-year project to prepare a plan to combat mental retardation in Kansas. The study is said to have been based on the principle that needs rather than diagnostic labels should determine services provided. Outlined are mental retardation planning activities at the federal level and preplanning activities in Kansas such as a 1958 report. Detailed is the organizational structure including 18 committees organized into three task forces. Information is provided on the incidence of mental retardation, existing and needed services, and future needs for program development. Described are research projects, training and demonstration projects, and legislative enactments concerned with mental retardation in public and private institutions in Kansas. Specific recommendations are given for the following areas: state organization, organization of community services, the need for a "fixed point of referral" at both community and state levels, diagnostic and evaluation services, parental counseling, home training, special education services, vocational rehabilitation, sheltered workshop services, the Vocational Rehabilitation Unit, state operated residential facilities, other residential facilities, group day care centers, prevention, research, public awareness, and manpower. Briefly explained is an implementation plan. (DB)

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Summary and Recommendations

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KANSAS CITIZENS PLAN
COMPREHENSIVE MENTAL RETARDATION SERVICES:

SUMMARY AND RECOMMENDATIONS

This study was supported in part by a Mental Retardation Planning Grant awarded by the Public Health Service, Department of Health, Education and Welfare.

Published by Division of Institutional Management
State Department of Social Welfare
State Office Building
Topeka, Kansas

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William H. Avery, Governor

August 1966

THE STATE OF KANSAS
OFFICE OF THE GOVERNOR
TOPEKA

WM. H. AVERY
GOVERNOR

August, 1966

To the Citizens of Kansas:

I present to you this summary document of mental retardation planning, and highly recommend that the contents be used as a guide in further planning, deliberations and action. The recommendations found herein point out the need for the citizens of Kansas to take responsibility in their communities to provide for the expansion and development of services for the mentally retarded. As Governor of the State of Kansas, I sincerely believe that the state can only assume leadership in the area of mental retardation when requested to do so by its informed and interested citizens.

It is my sincere hope that services can be developed throughout the state in order that we may meet the total needs for our mentally retarded.

Yours very truly,

Wm. H. Avery

Wm. H. Avery
Governor

WHA:ji

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STATE DEPARTMENT OF SOCIAL WELFARE
STATE OFFICE BUILDING
TOPEKA, KANSAS 66612

August 1966

To The Honorable Governor of Kansas:

This summary document, a guideline and plan for the development of comprehensive mental retardation services in Kansas, is the result of one and one-half years of planning by the citizens of Kansas. The planning project was conducted by the Division of Institutional Management of the State Department of Social Welfare.

During this planning project many Kansas citizens have brought forth numerous recommendations for initiation, expansion and development of needed services for the mentally retarded in our state. A summary of their recommendations, found in Chapter V, will hopefully be the foundation upon which we will proceed with implementation. The State Board of Social Welfare reviewed and discussed this plan on February 24, April 1, April 28, May 27, June 22, and July 29, 1966. To assist us in the review of this comprehensive document, a panel of specialists and representatives of organizations interested in the field of mental retardation were invited to participate and offer us their expert advise and counsel. These Kansans were: Elmer Ediger, Administrator, Prairie View Hospital; Mrs. Robert Wright, President, Kansas Association for Retarded Children; Herbert Miller, M.D., professor of Pediatrics, Kansas University Medical Center; Howard V. Bair, M.D., Superintendent, Parsons State Hospital and Training Center; Marguerite Thorsell, Ed.D., Director of Public School Programs for the Mentally Retarded, the Division of Special Education, Department of Public Instruction; Mr. Roger Triplett, Director Vocational Rehabilitation, State Board for Vocational Education; Duane Hetlinger, Ed.D., Emporia State College; Mrs. Dorothy Bradley, Director, Child Welfare Services, State Department of Social Welfare; Mrs. J. C. McKinney, President, The Association of Governing Boards of Community Mental Health Centers of Kansas; and Patricia Schloesser, M.D., Director, Maternal and Child Health Division, State Department of Health.

The review of this plan necessitated many hours of work, which resulted not only in preparation of this document but also in communication between agencies and private organizations that will be of ongoing significance.

This plan will not only be a prelude to further planning throughout the local communities of Kansas but will also be a guideline by which the legislature, the state departments, and the citizens as well begin making provisions for expanding needed services for the mentally retarded.

We forward these recommendations to you for your consideration, that of the Legislature, and citizens of Kansas, as we move ahead in our mental retardation programs.

Respectfully submitted,

Robert A. Anderson, Chairman
State Board of Social Welfare

Robert H. Jennison, Vice-Chairman
State Board of Social Welfare

Ross W. Zimmerman, Members
State Board of Social Welfare

Marvin E. Larson, Executive Secretary
State Board of Social Welfare

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August 1966

To The State Board of Social Welfare:

This document is the result of the efforts of hundreds of Kansas citizens working together to prepare a plan to combat mental retardation. Their planning effort followed the general principle that a mentally retarded person's needs, rather than his diagnostic label, should be prime determinant of the services he receives. This document summarizes the recommendations and findings by these citizens which have been previously published in the following documents: "Task Force Report Program Elements," "Task Force Report Life Stages," "Task Force Report Severity of Impairment," and "Mental Retardation Needs and Resources."

Chapter I of the summary document describes the planning activities at the Federal level and preplanning activities in Kansas.

Chapter II describes the organization of the planning processes followed during this year and a half project.

Chapter III presents an overview of mental retardation by describing the incidence of mental retardation, existing and needed services, and future needs for program development.

Chapter IV describes the research, training and demonstration projects, activities, and legislative enactments.

Chapter V is a summary of recommendations felt to be of primary concern needing immediate attention.

Chapter VI briefly describes a plan by which the citizens of Kansas can begin implementing needed services.

The Governor's Advisory Council on Mental Retardation Planning, the panel of specialists and representatives of organizations interested in mental retardation, who assisted in the review of this document, the eighteen planning task forces, and all others who have given time and effort through this total planning process should be highly commended for their efforts and knowledge that they have so freely contributed.

It is sincerely hoped that this document will serve as a guideline for action to be used by citizens of Kansas who have a concern and interest in the total welfare of the mentally retarded.

Very truly yours,

R. A. Haines, M.D.

R. A. HAINES, M.D., Director
Division of Institutional Management

KANSAS CITIZENS PLAN
COMPREHENSIVE MENTAL RETARDATION SERVICES:
SUMMARY AND RECOMMENDATIONS

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INTRODUCTION

This "Kansas Citizens Plan of Comprehensive Mental Retardation Services" is a composite of many hours of thought and deliberation by over 200 citizens throughout the state, concerned with the numerous problems which confront the mentally retarded in Kansas. Their concern follows the general principle that a retardate's needs, rather than his diagnostic label, should be the prime determinant of service which he should receive.

Chapter one of this "Plan" describes some of the planning activities at the federal level--President's Panel, President's Message to Congress, and Planning Legislation. It also contains an outline of the pre-planning activities which were conducted in Kansas prior to receipt of a federal grant to develop a plan to combat mental retardation. These activities include descriptions of Comprehensive Mental Health Planning, 1959 Report of the Governor's Committee on Mental Retardation, and a review of the Kansas State Report to the 1960 White House Conference on Children and Youth.

Chapter two describes the organization of the planning process followed in Kansas during this current planning project. Chapter three presents an overview of mental retardation by describing the incidence of mental retardation, existing and needed services, and future needs for program development. Cited within chapter four are notes on research, training and demonstration projects, activities, and legislative enactments during this planning period.

As a part of the planning project in Kansas, 18 planning committees were formed to study various areas of mental retardation. From the deliberations of these committees, hundreds of recommendations were submitted and printed in four documents--"Needs and Resources," "Severity of Impairment," "Life Stages," and "Program Elements." These recommendations were submitted to the Advisory Council on Mental Retardation and the State Board of Social Welfare who in turn reviewed and assessed the many recommendations--a summary of these compose chapter five. By closely studying the proposed recommendations, a distinguishable pattern-of-service for the mentally retarded begins to emerge. These patterns-of-service furnish a "plan for action," as found in chapter six, in order to implement the necessary needs and resources for the mentally retarded in the state of Kansas.

CHAPTER I

PRE-PLANNING ACTIVITIES

THE PRESIDENT'S PANEL ON MENTAL RETARDATION

The late President John F. Kennedy gave significant impetus to a nationwide program of planning to develop better services for the mentally retarded. One of his first steps was to appoint a panel to prepare a "national plan to combat mental retardation." This panel, appointed in October 1961, consisted of six "Task Forces." Each Force was assigned to study a particular segment of the overall problems of mental retardation and to prepare a comprehensive blueprint for national action. The panel was to review and make recommendations with regard to:

1. The personnel necessary to develop and apply the new knowledge. The present shortage of personnel is a major problem in our logistics. More physicians, nurses, social workers, educators, psychologists, and other trained workers are needed.

2. The major areas of concern that offer the most hope, and the means, the techniques and the private and governmental structures necessary to encourage research in these areas.

3. The present programs of treatment, education and rehabilitation.

4. The relationships between the federal government, the states and private resources in their common efforts to eliminate mental retardation.[1]

A collection of the six task force reports made up the Panel's report for the national program.

Within one year, the Panel presented its report to the President, entitled "A Proposed Program for National Action to Combat Mental Retardation." This report contained more than 90 recommendations concerning research and manpower, treatment and care, education and preparation for employment, legal protection and development of federal, state, and local programs for the mentally retarded.[2]

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[1] Mental Retardation, "A National Plan for a National Problem," Department of Health, Education, and Welfare, The President's Panel on Mental Retardation, Chart Book.

[2] Ibid.

THE PRESIDENT'S MESSAGE TO CONGRESS

"Pursuant to the many recommendations made by the Panel, the President outlined before the 88th Congress the program he considered necessary to combat mental retardation. A two-fold approach was specified as the key to the development of this comprehensive program. First, there must be public understanding and community planning available to meet the needs of the mentally retarded. Second, a concerted effort must be directed toward providing a continuum of services covering the entire range of the needs. Specifically, he recommended legislation to establish a program of special project grants to the states for financing state reviews of needs and programs in the field of mental retardation and to help stimulate public awareness in the development of comprehensive plans."[3]

THE WHITE HOUSE CONFERENCE ON MENTAL RETARDATION

In September 1963, the President called a conference with the following broad objectives:

1. To enable leaders in state and federal agencies concerned with mental retardation to become better acquainted.

2. To disseminate to state agencies information on current or pending mental retardation legislation which would be helpful to the states in the early and practical implementation of their own programs.

3. To stimulate examination by state and local agencies of their own needs and resources in the expectation that much could be done without legislation (or even new funds) by changes in procedures, by a new point of view, or by better inter-agency cooperation.

4. To learn of, and to increase our understanding of, the problems which state agencies may have in implementing their programs.

5. To enable all to share the experiences of others who have already blazed the trail in meeting some of these problems.

This conference emphasized the need for comprehensive state planning for mental retardation programs and services and approved many of the proposals outlined in the Report of the President's Panel on Mental Retardation. The political, social and scientific leaders who participated, unanimously agreed that the problem of mental retardation could no longer be hidden behind closed doors.

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[3] "Message from the President of the United States, Relative to Mental Retardation," House of Representatives, 88th Congress, Document No. 58; February 5, 1963.

PLANNING LEGISLATION

Congress voted favorably on the President's message and acted accordingly to pass Public Law 88-156. This law authorized grants to the states in the following areas and amounts for the fiscal year ending June 30, 1964.

1. Planning comprehensive action to combat mental retardation. $2.2 million.
2. Project grants for maternal and infant care. $5 million.
3. Increases in maternal and child health services. $35 million.
4. Increases in crippled children's services. $30 million.
5. Authorization for research relating to the last two programs.[4]

Upon submitting acceptable proposals, many states received grants from the federal government to begin to expand their planning activities to combat mental retardation.

Various activities had taken place in Kansas before Comprehensive Mental Retardation Planning began. The following pages will review this phase in order to provide a clearer picture of the basis on which planning is now conducted. It is intended to also show the value of research and other planning-related activities in the area of mental retardation.

REPORT OF THE GOVERNOR'S COMMITTEE ON MENTAL RETARDATION

In December 1958, Governor George Docking, of Kansas, appointed a committee of eight members* to study the problems and needs of the mentally retarded. From this study, the basis for a program to provide care and training was developed. This "Report of the Governor's Committee on Mental Retardation" was submitted in 1959. The recommendations contained in this report were:

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[4] "New Approaches to Mental Retardation and Mental Illness," Department of Health, Education, and Welfare, Office of the Secretary, White House Conference, 1963 Legislation; November, 1963.

* Chairmen: John E. King, President, the Kansas State Teachers College, Emporia Members: Adel F. Throckmorton, State Superintendent of Public Instruction, Topeka; Walter Arnold, Director, State Board for Vocational Education, Topeka; Frank Long*, Director, Division of Social Welfare, State Department of Social Welfare, Topeka; George W. Jackson, M.D., Director, Division of Institutional Management, State Department of Social Welfare, Topeka; Geoffrey M. Martin, M.D., Executive Secretary, State Board of Health, Topeka; Marvin Larson, Director, Division of Social Welfare, State Department of Social Welfare. Secretary: Tom Ladwig, the Kansas State Teachers College, Emporia.

1. "That additional community resources for the retarded be developed." Since the report was made, the number of community mental health centers has doubled. Federal and state day care funds are also being used to assist in financial support of community day care facilities.

2. "That Winfield State Hospital and Training Center not be expanded beyond its present size." As other programs for the retarded developed and as other facilities became available, the population was to be reduced to its normal capacity of 900. As recommended, plans for expanding Winfield were deferred and the unused money was reallotted. As the years passed, it has been possible to reduce the population.

3. "That Winter Veterans Hospital in Topeka be acquired by the state as a facility for the mentally retarded." The next session of the legislature made available acquisition and necessary appropriations for renovation and operation of the facility. Winter Veterans Hospital in Topeka was obtained from the federal government in July of 1959 and the Kansas Neurological Institute was opened in January 1960.

4. "That a survey of the size and nature of the problem of mental retardation be conducted by the State Board of Health." The Committee felt it would be extremely desirable to have better and more precise information about the number of mentally retarded in Kansas, their degree of retardation, and their annual increase. This recommendation was implemented in part as is evidenced in the 1960 White House Conference on Children and Youth Report which is described on page five.

5. "That statutory bias against mental retardation be removed from the laws of the state." In particular, the removal of the qualification "sound mind" from the definition of a crippled child was recommended. The 1965 session of the legislature has accomplished this specific removal of bias although, in general, much remains yet to be done for the retarded in this area.

6. "That the State Department of Health select an area for the adoption of a specific preventive program." The State Board of Health chose to initiate work in programs of prevention of phenylketonuria by locating and maintaining a registry of the gene carriers of this condition. Since the adoption of this program, 43 persons have become so identified as carriers of this condition. Legislation enacted by the 1965 session of the Kansas State Legislature has made testing for phenylketonuria in newborn children mandatory.

7. "That legislation be enacted which would enable the State Board for Vocational Education to broaden services to the mentally retarded and that counselors be provided for in the 1961 budget of this agency." The law, as asked, was passed and funds were appropriated for the creation of a Rehabilitation Unit for evaluation and work adjustment.

8. "That the 1960 Kansas Legislature consider an increased reimbursement rate of $1,500 to $3,000 for each special public school class for the educable retarded." This proposal asked also for an increase in the reimbursement rate to $3,000 for each full-time special teacher for the trainable retarded. In both instances, it was recommended that all other reimbursement factors be retained. The

legislature was also asked to provide additional consultative staff at state or regional level for the educable and trainable retarded. The reimbursement rate was increased to $2,500 for the educable and $2,000 for the trainable retarded, and the reimbursement factors were retained. However, to date, no substantial action has been taken with regard to the recommendation directed toward enlarging consultative staff and services in the state's special education programs.

9. "That the 'Governor's Committee on Mental Retardation' remain active indefinitely and meet at least twice each year to assist in the future development of a sound program to aid the mentally retarded and their families." While this would have provided an ideal basis for transition into the present planning activities and may have done much to implement proposals made by this committee, this recommendation was never carried through and activities of this body were concluded with submission of its report.[5]

KANSAS STATE REPORT TO THE 1960 WHITE HOUSE CONFERENCE ON CHILDREN AND YOUTH--REPORT ON EXPANSION OF SERVICES FOR THE MENTALLY RETARDED.

The Kansas sub-committee on health elected "Expansion of Services to the Mentally Retarded" as one of seven topical areas for study in the 1960 White House Conference. The remaining six areas of study were:

1. The Effects of Frequent Family Moves on the Mental Health of Children
2. The Effects of Early Marriage and Childbearing
3. Report on the Rehabilitation of the Handicapped Child
4. Report on Accidents as a Problem of Children and Youth
5. Report on Progress in Extending Prepaid Health Care Benefits to Include Children and Youth--1950-59
6. Report on Well Child Supervision in Kansas[6]

The report on Expansion of Services to the Mentally Retarded by the study group on mental retardation* was submitted by the Kansas delegation to the 1960 White House Conference. This report evidenced a true awareness in Kansas that the mentally retarded have not only the same right, but a crucial need to realize their full potential, and to live their lives with the same freedom and dignity allowed other citizens.

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[5] Mental Retardation, "Report of the Governor's Committee;" September, 1959.

[6] "Governor's Steering Committee on White House Conference Planning, the 1960 White House Conference on Children and Youth," November, 1959.

* Mrs. Barbara Edmonson, Mr. H. E. Drantz, Fae Spurlock, M.D., and Mrs. Adrian Miller, Chairman.

Most emphatically, the problem in Kansas at that time was expressed by the following:

> "There seems to be a need for coordinated, cooperative planning, plus implementation of plans and communication between the various departments; for all to understand just what services each either actually does, or does not offer, with the firm understanding that these are interacting services between all."[7]

KANSAS COMPREHENSIVE MENTAL HEALTH PLANNING

The Kansas Comprehensive Mental Health Planning program began in the summer of 1963. Financed by a grant from the National Institute of Mental Health, it was administered by the State Board of Social Welfare, Division of Institutional Management, Community Mental Health Services, which had been designated by the Governor as the state mental health authority. The Board, in turn, appointed planning committees, charging them to study the problem of mental health and recommend solutions. Recommendations submitted included some concerning the needs of the retarded. Reports of the planning committees emphasized that the activities relating to mental retardation necessitated closer coordination of efforts at the state, regional, and local level.

At the regional and local level, the already existing 22 mental health centers appear as an important element in providing some facets of coordinated services for the retarded. These centers are supported by counties occupied by 75% of the state's population. As a blueprint for future development of these vital aspects in comprehensive mental health services, 25 mental health planning districts were drawn up, sectoring the state into a number of smaller, serviceable sections. With the subsequent formation of three additional centers, each planning district would thereby house and be serviced by a community mental health center. Eleven of these 25 centers, it was further recommended, should expand their services so as to provide "comprehensive care" in the form of outpatient, inpatient, day hospital, rehabilitation, and services for the mentally retarded in a multi-district mental health and mental retardation services area. A more extensive description on this subject may be found in chapter five under the heading "Organization of Community Services."

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7 Ibid.

CHAPTER II

ORGANIZATION OF THE PLANNING PROCESS

In 1964, the State Board of Social Welfare was designated by the Governor as the state agency responsible for comprehensive planning for mental retardation. The Board vested the Division of Institutional Management with the responsibility for mental retardation planning. At the same time a 19-member Advisory Council on Mental Retardation Planning was appointed by the Governor, John Anderson, with the Director of the Division of Institutional Management serving as Chairman. Members appointed to this council were heads of state agencies, private agencies and organizations. They represented the fields of health, education, welfare, employment, rehabilitation, and law, among others. The Council was charged with the task of assisting the Division's Community Mental Health Services carry out the activities of the planning process. (See Chart #1)

In April of 1964, Kansas submitted an application proposal for grant funds to assist in planning. In July of 1964, the Kansas proposal was approved, with the State receiving project funds to carry out the planning activities included in and specified by its proposal.

Principles of Planning

In accordance with the limits set by authorizing legislation, grant funds for mental retardation planning were to be used to determine the action needed to combat mental retardation in the State and the resources available for this purpose; to develop public awareness of the scope of mental retardation and of the need for combating it; to coordinate state and local activities relating to the various aspects of mental retardation and its prevention, treatment, or amelioration; and to plan other activities leading to comprehensive state and community action to combat mental retardation.

Three basic concepts guided the thinking and deliberations of planning committees. First, planning was to be comprehensive. It would be concerned with the needs and problems of the retarded of all age levels and of all degrees of severity of impairment. Effort would be directed not only toward providing direct diagnostic, treatment, training, and educational services, but also toward the broader areas of prevention, research, public education, continuing education and in-service training for professionals, recruitment, manpower, and finances. Recognizing that mental retardation is not the province of one profession or one agency, but requires the skills, knowledge, and resources of many professions and agencies, the planning committees included representatives from the fields of health, education, welfare, employment, rehabilitation and law.

Second, planning emphasized coordination. It was concerned with better use and coordination of existing services and programs as well as development of further needed resources in a synchronized manner. The goal was to obtain a program that allowed the retarded individual and his family to obtain immediate

access to all appropriate services at any given point in time, allowing for a smooth progression as later services and programs became necessary, with as little disruption of normal family life as possible.

Third, planning was to encompass continuous services and programs. A continuum of care was stressed, with appropriate resources and services being readily available to the retarded individual and his family over the entire life-span. Specific attention was given to providing a fixed point of referral to which the retarded person and his family could turn for guidance, counseling, and information pertaining to all programs and resources associated with mental retardation.

These three principles--(1) comprehensiveness, (2) coordination, and (3) continuum of care--formed the nucleus of concern in planning for the retarded in Kansas and served as the central reference points around which the rest of the planning was organized. (See Chart #2)

Planning Activities

I. Information and Fact Finding: Activities included in this phase formed the informational basis upon which subsequent activities were supported and conducted.

   a. Survey of Resources: An intensive and comprehensive survey of all resources for the mentally retarded and their families was conducted during the summer and early fall of 1964. All relevant agencies of state and local levels were contacted. Information pertaining to present programs, services, facilities, staffing, and future needs was obtained.

   b. Prevalence and Incidence Study: The prevalence and incidence of mental retardation in Kansas was determined by using census reports and percentage estimates found to be reliable and valid from previous studies in various parts of the United States. Estimates of mental retardation were made on a county and regional basis and were classified according to degree of impairment and age level.

   c. Regional Meetings: Six regional meetings were held throughout the state with professional persons and lay leaders in each of the regions. The purpose of the meetings was to foster awareness of the need for each region to plan for a coordination of services, to keep informed of statewide planning activities, and to obtain in each region the thinking about needed resources and programs. Through these meetings, the special problems and particular circumstances and conditions of each region became known.

II. Preliminary design of program elements: Supported by information collected in the first phase, committee reports in this phase were to contain all the preliminary units from which a comprehensive program could be designed.

a. Planning Committees: Eighteen committees were organized into three "Task Forces," to develop a report specifying recommendations for needed services and programs in each of their respective areas. Committees were composed of a number of citizens representing a wide variety of relevant interests and professions and included the fields of health, education, welfare, vocational rehabilitation, employment, law, and community and institutional services. (Chart #2a summarizes the organization and assignments of the "Task Forces" and committees.)

b. Consultation Panel: To give the planning further support and representation, a six-member "Consultation Panel on Mental Retardation Planning" was chosen (See Appendix B.). Members were asked to participate on the basis of knowledgeability and competence in areas allied to the field of mental retardation. They were called upon to meet periodically to review and assess the planning process.

III. Integrative Phase of Operations: Activities in this phase were designed to bring all the fundamental units and preliminary design elements into one unified plan through 1) application of the planning principles and concepts, and 2) rating of recommendations by the Advisory Council on Mental Retardation Planning. (See Appendix A.)

IV. Output: Summarizing committees in this phase presented, in an understandable way, the recommendations resulting from planning to the total community of Kansas. Reports of all committees were published and distributed widely throughout the planning process.

This final document includes revisions deemed necessary by the State Board of Social Welfare. Upon its acceptance by the Board, the document with its recommendations will be presented to the Governor and the State Legislature for their consideration and implementation.

Chart #1 Structure of Planning Administration

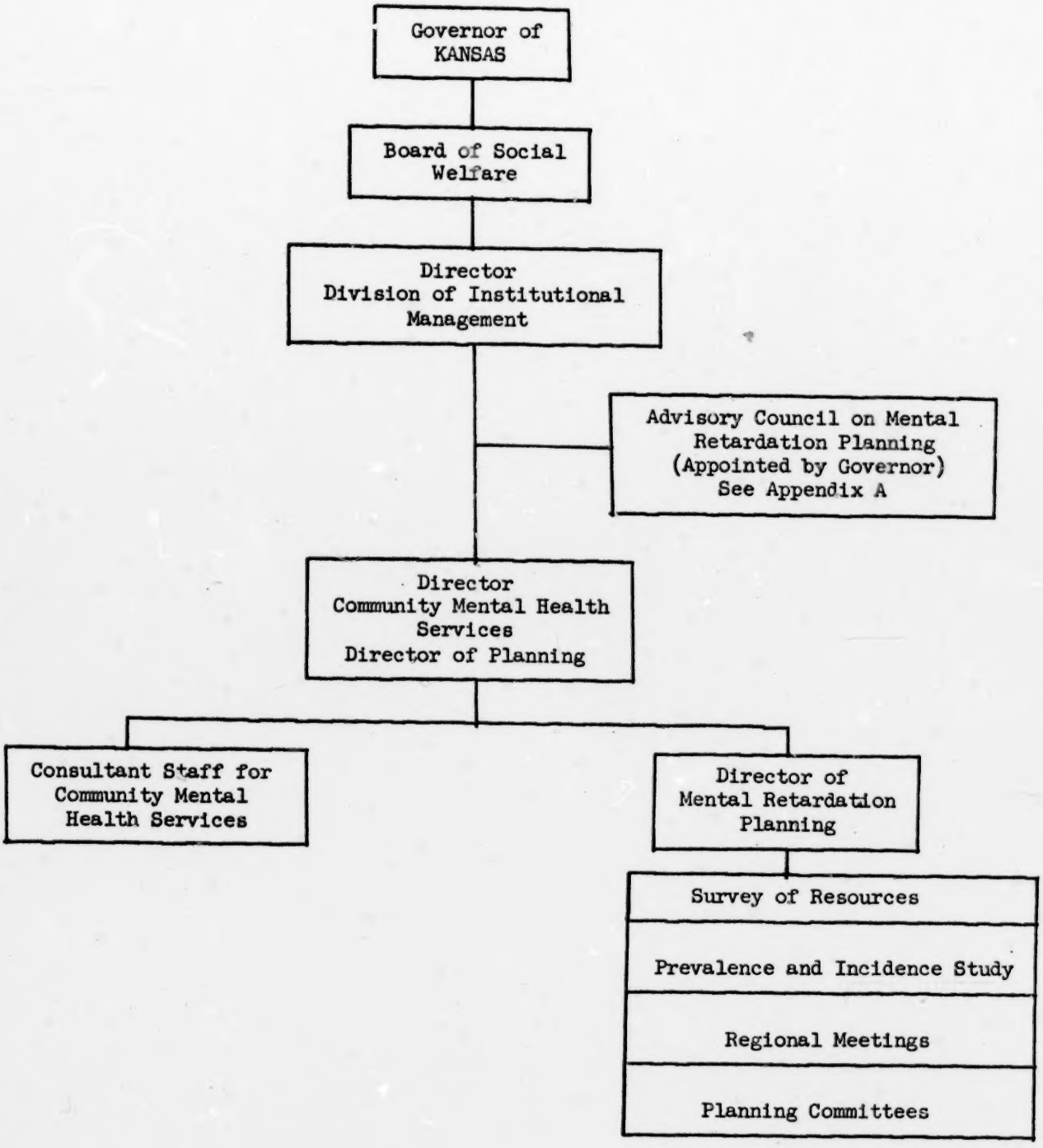
Governor of KANSAS
Board of Social Welfare
Director Division of Institutional Management
Advisory Council on Mental Retardation Planning (Appointed by Governor) See Appendix A
Director Community Mental Health Services Director of Planning
Consultant Staff for Community Mental Health Services
Director of Mental Retardation Planning
Survey of Resources
Prevalence and Incidence Study
Regional Meetings
Planning Committees

CHART #2
STRUCTURE OF PLANNING ACTIVITIES

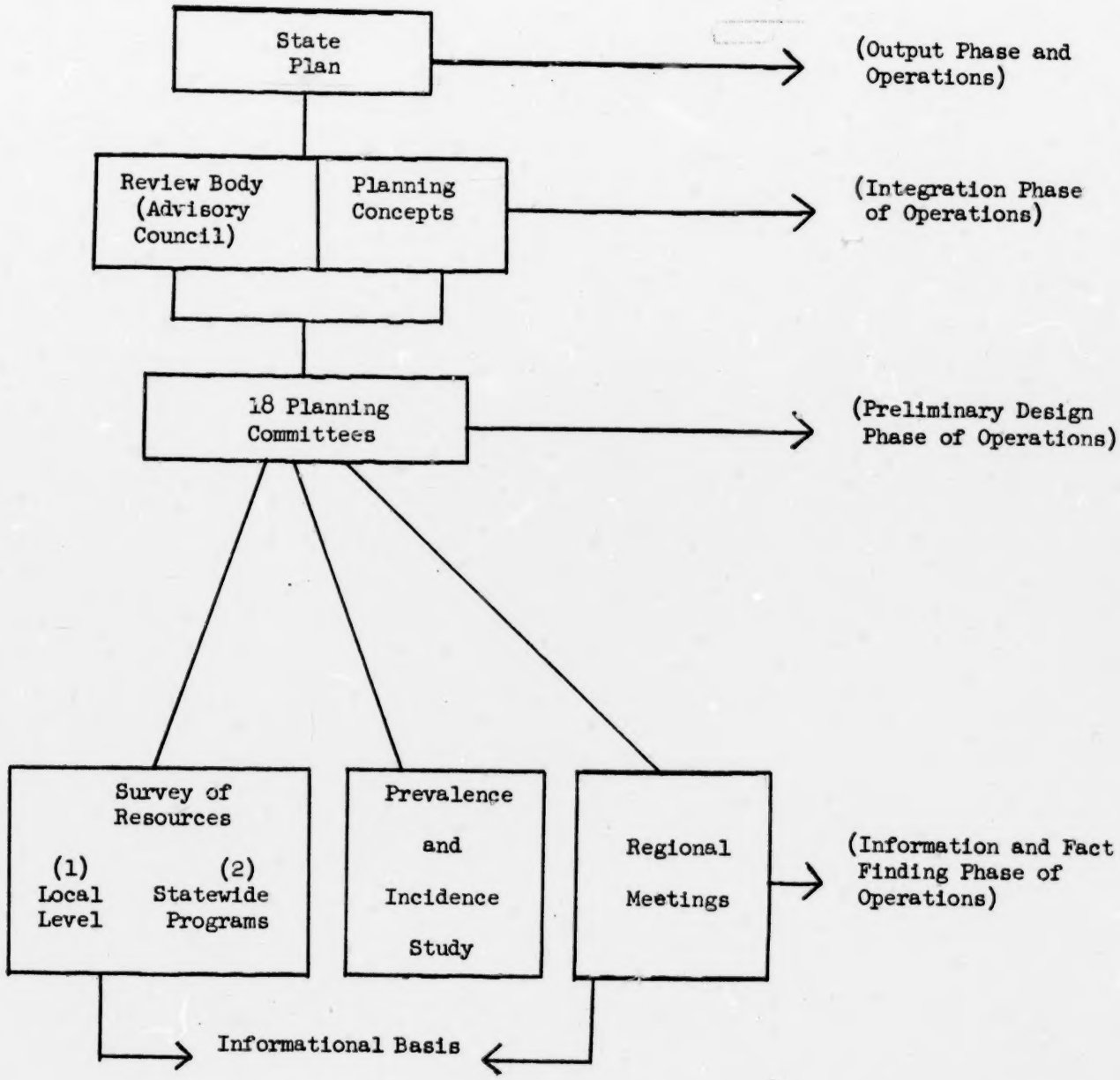

Chart #2a
ORGANIZATIONAL CHART OF
18 PLANNING COMMITTEES

Task Force I: Life Stage Committees

Life Stage Committee 1: Perinatal
Life Stage Committee 2: Preschool
Life Stage Committee 3: School Age
Life Stage Committee 4: Adolescent
Life Stage Committee 5: Adult

Task Force II: Topical Area Committees

(1) Committee on Coordination of State Governmental Agency Activity in Mental Retardation
(2) Committee on Coordination of Institutional and Community-Based Programs
(3) Committee on Finance
(4) Committee on Manpower
(5) Committee on Research
(6) Committee on Prevention and Control
(7) Committee on Legal Aspects of Mental Retardation
(8) Committee on Socio-Cultural Trends
(9) Committee on Continuing Education
(10) Committee on Public Awareness and Education

Task Force III: Severity of Impairment Committee

(1) Committee on Mild (Educable) Retardation
(2) Committee on Moderate (Trainable) Retardation
(3) Committee on Severe Retardation

CHAPTER III

OVERVIEW OF MENTAL RETARDATION

Attempts to classify and define a problem as complex as mental retardation have resulted in nearly as many basic descriptions as there are approaches to viewing the problem. A chief difficulty in trying to formulate a precise definition of mental retardation is that the term, itself, may be used to refer to a heterogeneous group of individuals whose disabilities are dissimilar not only in causative origin but also in resulting degree of impairment. In the realm of physical pathology, any one of a number of various impairments to the nervous system can result in an appreciably decreased intellectual capacity, also resulting in an inability to function effectively in response to demands of the environment. While it is not always possible to trace the intellectual disability back to any demonstrable physical or nervous pathology of the brain, mental retardation can, nevertheless, be considered as a disability residing within the individual which can spring from any number of internal physical, or external environmental causative agents. Thus, there may be as many basic descriptions of mental retardation as there are approaches, which range between pinpointing and broadly outlining causative factors.

While definitions are undoubtedly important to our growing knowledge of retardation, it must be pointed out again that cases of retardation where central nervous system pathology is an obvious facture account for not more than 20 percent of all retarded. Disabilities of this nature occur proportionately equal throughout all socio-economic, ethnic, and racial groups, nearly always producing a similar disorder with IQ's falling below 55.

In contrast, for nearly 80 percent of the retarded cases, it is not possible to discern such obvious and gross pathology of the central nervous system. The largest number of this group usually appear to be physically normal but function intellectually as mentally retarded. Some of these people can be said to have derived their condition from having been reared in socially and economically disadvantaged environments. The precise cause of retardation in this group of individuals is mostly unknown, except that it is largely found to accompany living in deprived social and economic circumstances. While inheritance of intelligence undoubtedly may play a significant role, other important factors may also be involved. Poor prenatal care among low socio-economic group mothers, high rates of prematurity, inadequate infant health supervision, and other factors may all be related to producing mild central nervous system defects not discernable under present methods of physical examination. More importantly, however, there is evidence that poor motivation and lack of interest in intellectual development and achievement, combined with restrictions in learning opportunities, are significant contributing etiological factors in this group. These retarded individuals are most often classified as mildly retarded and they range between 50 to 80 in measured intelligence. This IQ range is usually considered to be educable and generally these individuals fall into the mild and moderate degrees of impairment in adaptive behavior in adult life.

A highly useful definition, believed to include the total range of mental retardation, was published by the American Association on Mental Deficiency: "Mental retardation refers to sub-average general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior.

"The definition specifies that the sub-average intellectual functioning must be reflected by IMPAIRMENT IN ADAPTIVE BEHAVIOR. Adaptive behavior refers primarily to the effectiveness of the individual in adapting to the natural and social demands of his environment. Impaired adaptive behavior may be reflected in: (1) maturation, (2) learning, and/or (3) social adjustment. These three aspects of adaptation are of different importance as qualifying conditions of mental retardation for different age groups.

> "(1) Rate of MATURATION refers to the rate of sequential development of self-help skills of infancy and early childhood such as, sitting, crawling, standing, walking, talking, habit training, and interaction with age peers. In the first few years of life adaptive behavior is assessed almost completely in terms of these and other manifestations of sensory-motor development. Consequently, delay in acquisition of early developmental skills is of prime importance as a criterion of mental retardation during the pre-school years.
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> "(2) LEARNING ability refers to the facility with which knowledge is acquired as a function of experience. Learning difficulties are usually most manifest in the academic situation and if mild in degree may not even become apparent until the child enters school. Impaired learning ability is, therefore, particularly important as a qualifying condition of mental retardation during the school years.
>
> "(3) SOCIAL ADJUSTMENT is particularly important as a qualifying condition of mental retardation at the adult level where it is assessed in terms of the degree to which the individual is able to maintain himself independently in the community and in gainful employment as well as by his ability to meet and conform to other personal and social responsibilities and standards set by the community. During the pre-school and school age years social adjustment is reflected, in large measure, in the level and manner in which the child relates to parents, other adults, and age peers.
>
> "It is this accompanying deficiency in one or more of these three aspects of adaptation which determines the need of the individual for professional services and/or legal action as a mentally retarded person. Delayed maturation in the pre-school years, for example, is the primary basis for referral to medical clinics. Impairment in learning ability at the school-age level creates a need for specialized educational services and at the adult level inadequate social adjustment creates a need for supportive and remediative vocational and welfare services."[8]

Adaptive behavior is a composite of many aspects and the function of a wide range of specific abilities and disabilities. Behaviors classified under the designations of intellectual, affective, motivational, social, motor, etc., all contribute to and are a part of total adaptation to the environment. Addition of the "adaptive behavior" dimension to that of measured intelligence, is important in many respects and is best expressed by the following quote from an authority in the field attempting to make much the same point:

> "...although we shall be concerned primarily with sources of retardation rooted in the individual and his environment, we must pay equal attention to

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[8] A Manual on Terminology and Classification in Mental Retardation, Monograph Supplement to American Journal of Mental Deficiency, Second Edition, 1961.

the way in which the society defines, perceives, reacts to, and attempts to cope with mental subnormality regardless of its origin. Even a child with a severe defect must be viewed as deificent relative to cultural standards of acceptability; the cause of this deficiency may be organic but its magnitude is dependent upon social criteria."[9]

MENTAL RETARDATION AND MENTAL ILLNESS

"Mental retardation is usually a condition resulting from developmental abnormalities that start prenatally and manifest themselves during the newborn or early childhood period. Mental illness, on the other hand, includes problems of personality and behavioral disorders especially involving the emotions; it usually manifests itself in young or old adults after a period of relatively normal development.

"There is always a deficit in intellectual function in mental retardation; mental illness may or may not involve such a defect... The two problems are related in that they may occur in the same patient and frequently involve some of the same kinds of professional skills to diagnose or assist the patient. On the other hand, each problem does occur independently of the other and adequate professional skill to deal with one problem does not assure competency to deal with the other. The ability to distinguish clearly between these problems in a given patient and to deal with each appropriately is often the crux of good care."[10]

Although this distinction is generally recognized by professionals working in the fields of mental health and mental retardation, the state of Kansas has felt it more advisable to have the administration of these programs under the State Board of Social Welfare. This type of administrative structure has enabled Kansas to provide service for the individual's needs rather than his diagnostic label of being mentally retarded, mentally ill, or both.

INCIDENCE OF RETARDATION AND EXISTING AND NEEDED SERVICES IN KANSAS

Using intelligence as the sole determining factor of a person's ability to function, the performance of three percent of our national population can be classified as being mentally retarded. This three percent figure, pertaining to individuals with an IQ of 70 or less, is based upon indices generally accepted by

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9 Sarason, et.a., Mental Subnormality, p. 145.

10 "New Approaches to Mental Retardation and Mental Illness," Welfare Publication Indicators, November, 1963 reprint.

authorities in the field and was used by the President's Panel on Mental Retardation. If the intelligence quotients were raised to 75 or 80, we would have to consider the percentage of our retarded population increasing from three percent to approximately 16 percent or 352,000 retarded individuals. However, considering in this plan only the three percent rate and the state's 1965 population figures, there are, in round numbers, 66,000 mentally retarded individuals in Kansas today. Unless there is a major breakthrough on the preventative level not foreseen at this time, the number of retarded individuals in Kansas can be expected to increase at the rate of at least 800 per year.

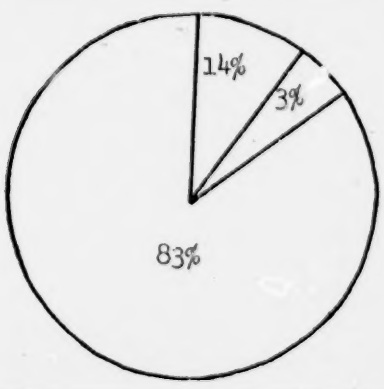
Within this retarded population, there is a variation in the degree of retardation or severity of impairment. These individuals can be classified roughly according to three broad groups. (These figures represent a 1965 study of all ages of retarded individuals.)

1. Educable or Mildly Retarded: These are individuals presently unable to profit to any great degree from the program of regular schools but who have potentialities for development of (a) minimum educability: reading, writing, spelling, arithmetic, and so forth; (b) capacity for social adjustment to a point where they can get along independently in the community; and (c) minimum occupational skills to support themselves partially, or totally at a marginal level. These individuals represent about 83 percent of the retarded population. In Kansas, about 55,000 individuals are mildly retarded or educable.

2. Trainable or Moderately Retarded: These are individuals presently unable to profit from classes for educable mentally retarded but who have potentialities in three areas: (a) learning self-care and activities such as eating, dressing, undressing, toileting, and sleeping; (b) learning to adjust in the home or neighborhood, though not to the total community; and (c) learning about economic usefulness in the home, sheltered workshop, or an institution. These individuals represent about 14 percent of the retarded population in Kansas--9,200.

3. Severely and Profoundly Retarded: These are individuals who will require almost continual supervision and care throughout their lives. Some can conform to daily routines and repetitive activities, but most will be unable to meet their self-care and personal needs. These individuals represent about three percent of the retarded population in Kansas--2,000.

KANSAS PERCENTAGE OF RETARDED POPULATION
IN RELATION TO SEVERITY OF IMPAIRMENT



14% - Trainable

3% - Profound

83% - Educable

There is also a large number of individuals in our society, both in and out of our school system, who are displaying some of the same learning disabilities as the mentally retarded. Individuals classified in this group possess IQ ranges of not more than 80 nor less than 70. This would then add another level to our retarded ranges, indicating that 16 percent of our total Kansas population have learning difficulties rather than the 3 percent figure generally used in mental retardation classification.

MAJOR SERVICES AND RESOURCES

Broadly conceived, there are several major resources for the mentally retarded in Kansas which provide specialized training and/or services to meet their numerous needs. One resource generally first thought of in Kansas is the state institutions for the mentally retarded which served a total of 2,420 patients in 1965. These institutions provide services for the following types of patients:

> "Parsons State Hospital and Training Center. Ambulatory (not multi-handicapped) persons who are mentally deficient or retarded with an IQ below 50, who are six (6) years of age and not over twenty-one (21) years of age, may be admitted to the Parsons State Hospital and Training Center. Children with an IQ between 50 and 70 are eligible for admission to Parsons State Hospital and Training Center only if they require treatment or training not provided by special classes in the public schools."[11] Patients served in 1965 totaled 728.
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> "Winfield State Hospital and Training Center. Ambulatory persons who are mentally deficient or retarded with an IQ below 50, and who are over two (2) years of age and under (6) six years of age or who are over twenty-one (21) years of age; non-ambulatory persons or multi-handicapped persons of any age who are mentally deficient with an IQ below 50 may be admitted to the Winfield State Hospital and Training Center. Children with an IQ between 50 and 70 are eligible for admission to Winfield State Hospital and Training Center only if they require treatment or training not provided by special classes in the public schools."[12] Persons served in Fiscal Year 1965 totaled 1,178.
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> "Kansas Neurological Institute. Persons who are mentally deficient or retarded with an IQ below 50, who are between the ages of two (2) and twenty-one (21), may be admitted to Kansas Neurological Institute. Mentally retarded persons who are multi-handicapped, under age two (2), may be admitted to Kansas Neurological Institute. Children with an IQ between 50 and 70 are eligible for admission to Kansas Neurological Institute only if they require evaluation, treatment or training not provided by special classes in the public schools."[13] The total patients served in Fiscal Year 1965 totaled 436.

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[11] Manual of Regulations, Division of Institutional Management, Article 23, "Parsons State Hospital and Training Center, Winfield State Hospital and Training Center, and Kansas Neurological Institute," (1960)
(This manual is being revised since adaptive behavior is being used in determining whether or not an individual needs residential care.)

[12] Ibid.

[13] Ibid.

The State Sanatorium for Tuberculosis, at Norton, has a limited neuro-psychiatric section for ambulatory retarded individuals transferred from the other hospitals for the retarded. Patients served in fiscal year of 1965 numbered 124.

There are other fields of service throughout the state which provide programs for the mentally retarded. These specific fields are outlined as follows:

The Division of Vocational Rehabilitation of the State Department of Vocational Education has been active in working with the mentally retarded since January, 1961. The primary emphasis has been providing services in the Vocational Rehabilitation Unit on the grounds of Kansas Neurological Institute at Topeka.

Since 1961, over 600 mentally retarded individuals have been served by the Vocational Rehabilitation Unit--at any given time, about 150 individuals are receiving this service. The figure 150 includes individuals in residence at the Unit and those who have moved to outside placement and are still being provided with counseling and other follow-up services. The primary services offered by the Unit are vocational evaluation, vocational and personal adjustment training, counseling and guidance, job placement, and follow-up service. Various other rehabilitation services which cannot be provided at the Unit are purchased from outside sources. This Unit is one of the few in the nation specifically serving the mentally retarded with this type of program.

The University of Kansas Medical Center has been a leading service in the state's mental retardation program. During the year 1964-1965, this hospital conducted 12 school room classes for 150 children between 4 and 16 years of age. Sixty-three members in these classes were classified as mentally retarded or orthopedically handicapped. (Many of the children classified as orthopedically handicapped could also be classified as mentally retarded.) These figures point out that 42% of the children in this total program were mentally retarded. Many of these students also received regular therapy from adjunctive services such as occupational therapy, physical therapy, and speech and hearing. The staff evaluated an additional 105 children with mental retardation or learning disabilities, and 541 children with hearing and speech problems.

The Birth Defects Center, located in the Pediatrics Department Clinic, at the University of Kansas Medical Center is another service interested in and functioning to assist the mentally retarded. Its main purpose is to organize and provide comprehensive diagnosis, treatment, and follow-up care for the children referred to the hospital. These children have multiple handicaps such as phenylketonuria, post-rubella syndrome, or are mentally retarded for whatever cause. Several hundred children in these categories register in the Birth Defects Center each year. The Birth Defects Center thus organizes the extensive medical services to handicapped children, while the Children's Rehabilitation Unit at the hospital organizes the training programs. The two units mutually support each other to benefit the retarded.

The Division of Special Education of the State Department of Public Instruction has been active in providing classrooms for the mentally retarded. In the 1965-1966 school year, this department worked with 261 classes for mildly (educable) retarded individuals in public schools. With an average of 13 students per class, the total number of children served was 3,393. There were also 23 classes for moderately retarded, with an average enrollment of 9.1 each. In summary, public schools are currently serving 3,600 mentally retarded individuals in the day school classes throughout the state of Kansas.

There is an increased interest for developing new and additional programs for the mentally retarded in the senior high schools, primarily programs for mildly (educable) retarded, and in expanding moderately (trainable) retarded programs to include more teenage groups. This expansion would provide more services for a larger number of retardates who could profit by attending such classes.

The State Department of Health has been another very active field of service to the mentally retarded. This department has made a provision for matching funds to county health departments for hiring additional nurses to work with families of retarded children. This provision states that one third of their time and activities must be spent in mental retardation work. To date, eight counties have hired one or more nurses on a contractual basis with this department. The Department of Health has employed public health nurses, involving them in investigation of the environmental standards of boarding homes, day care centers and other children's facilities which serve the mentally retarded. This department is also providing laboratory services for screening all newborns for phenylketonuria, and is conducting an educational program concerning this disease. Since initiating this service, 47 cases of PKU have been detected. The Division of Health Education Services of the State Department of Health has continued to conduct a statewide education program in the area of mental retardation. They have continued to maintain an up-to-date film library, in addition to their current pamphlets.

COMPREHENSIVE DIAGNOSTIC AND EVALUATION FACILITIES IN KANSAS

It is quite evident that expansion of existing, and provisions for new diagnostic and evaluation facilities for the mentally retarded are vitally needed in Kansas. There are presently five comprehensive diagnostic and evaluation facilities in Kansas. They are:

1. Kansas Neurological Institute - Topeka.
2. University of Kansas Medical Center - Kansas City, Kansas.
3. Parsons State Hospital and Training Center - Parsons.
4. Winfield State Hospital and Training Center - Winfield.
5. Menninger Foundation - Topeka.

Various other facilities throughout the state provide for partial diagnosis and evaluation of the retarded, such as mental health centers, general hospitals, vocational rehabilitation units, employment offices, schools, etc. However, these facilities are presently unable to provide as extensive an evaluation as the five facilities named above.

FUTURE NEEDS FOR PROGRAM DEVELOPMENT

To deal effectively with the scope and complexity of mental retardation, it is clear that a pattern of services is needed. A beginning may be in establishing casefinding services that will identify retarded individuals and then continuing with diagnostic and evaluation services to provide a sound basis for planning. A pattern of services must be devised that will insure a full range of care over the entire life of the retarded. Some essential elements needed for such a program are outlined in a publication of the American Journal on Mental Deficiency entitled "A Manual of Program Development in Mental Retardation." This resource represents one grouping of the number of services needed for an array of programs which most professionals agree should be developed. These are:

1. Basic Prevention
2. Diagnosis
3. Counseling for Retarded Individuals and Parents
4. Social Adjustment Day Centers
5. Residential Care
6. Long-Term Supervision and Guidance
7. Casefinding
8. Home Training
9. Nursery Classes
10. Special Education
11. Adult Education
12. Vocational Training and Counseling
13. Sheltered Workshops
14. Day Care
15. Foster Home, Half-Way House, Community Residential Living
16. Recreation
17. Research
18. Training of Personnel
19. Public Education

In addition to developing programs, an adequate supply of manpower to operate the programs must be found. There is a tremendous demand for the services of special education teachers, social workers, public health nurses, and other professional and lay citizens skilled in working with the retarded.

It has been continually stressed that our state educational institutions should emphasize the education and training of personnel to meet the needs of the mentally retarded citizens of the state. It is hoped that the various professional training programs in our colleges be expanded and that existing agencies can be used for training purposes. It has also been suggested that a stepped-up program of inservice training be made available for all individuals working with the mentally retarded.

CHAPTER IV

RESEARCH, ACTIVITIES, AND LEGISLATION

Research, legislation, and various other activities concerning mental retardation in the past two years in Kansas have produced a great amount of current information and knowledge of interest to professionals, institutions, the legislature, and most of all, to lay citizens--mainly parents of the mentally retarded. Through the activity of professionals, institutions, and citizens, new and far-reaching programs are being developed. The following is a review of some of the projects being conducted and planned by various state agencies and institutions during this period. These projects demonstrate the fact that Kansas is moving ahead in its attempt to combat mental retardation. The following is the latest information available, but is not all inclusive as new projects of all types are continually being developed.

RESEARCH, DEMONSTRATION AND TRAINING PROJECTS

Research in Kansas has enabled the citizens of this state and of the nation to deal more effectively with problems of mental retardation. Many projects have been undertaken by professionals of all disciplines, pointing out the magnitude with which this problem touches the entire life span of the retarded. Some of the research, demonstration and training projects are as follows:

I. The Center for Research in Mental Retardation:

The Center for Research in Mental Retardation approved for a federal grant, January 1966, will utilize staff activities at Parsons State Hospital and Training Center, the University of Kansas in Lawrence and the University of Kansas Medical Center in Kansas City, Kansas. The research program will be focused especially on several biological science areas--i.e., genetics and early reproduction, biochemistry and metabolism, fetal and neonatal pathophysiology and neurophysiology--and several behavioral science areas pertaining to behavioral assessment and modification--i.e., learning and retention, language development, social behavior, and environmental consequences.

The Center will include construction at the University of Kansas Medical Center, University of Kansas at Lawrence, and Parsons State Hospital and Training Center. Each facility is designed to utilize the special resources of its setting and each would permit further expansion if program plans were enlarged.

The administrative plan of the Center includes an Administrative Committee made up of the Provost of the University, Chairman; the Dean of the Medical Center, and the Superintendent of Parsons State Hospital and Training Center. In addition, the Center will have a Coordination Committee made up of:

The Associate Dean of Faculties for Research (KU)
The Associate Dean for Research (KUMC)
The Research Director (KUMC facility)
The Research Director (KU facility)
The Research Director (Parsons facility)
The Coordinator of Research for the Bureau of Child Research
The Coordinator of the Center, Chairman

Center research planning will be expedited by a scientific advisory committee made up of appointed members drawn from the staff of principal investigators. This committee includes at least two representatives of each setting.

The unique multi-inter-disciplinary aspects of the university-institution affiliation provide the ideal setting for strengthening efforts to deal with the acute shortage of clinical personnel in the field of mental retardation. Accordingly, a proposal is being submitted to the United States Public Health Service for assistance under its matching-fund program for university-affiliated clinical training facilities. If approved, Kansas will be one of the first of the 50 states to have related research and clinical training programs and facilities as provided in the new PHS Legislation.

Prior to the origin of the Kansas Center for Research, as it is now known, unique cooperation and inter-relationships were established by personnel at these three locations while engaging in research in the area of mental retardation. Parsons State Hospital and Training Center affiliated with the Bureau of Child Research at the University of Kansas, and operated research programs under the sponsoship of the National Institute of Mental Health and the National Institute of Neurological Diseases and Blindness from 1957 to 1965, receiving substantial funds under a policy of annual grant renewal.

In 1963, this research program was enlarged and stabilized with transfer of federal authority from the National Institute of Mental Health to the newly created National Institute of Child Health and Human Development. Grant awards from that agency totaled $2 million over a seven-year period. The long-term funding provisions of the new arrangement not only authorized expansion of the Parsons research effort, but also provided grants for new projects at the Bureau and at the Children's Rehabilitation Unit of the University of Kansas Medical Center in Kansas City.

One of the research projects studied by the three institutions before the Center was established was entitled "Communication Disorders of Mentally Retarded Children." Studies being conducted under the seven-year project have the following seven major objectives:

1. Continued development and evaluation of approaches to communication behavior of retarded children;
2. Investigation of learning and retention processes of retarded and normal children;
3. Investigation of language development of retarded and normal children;

4. Investigation of social interaction of retarded and normal children in laboratory situations;
5. Investigation of social behavior of retarded children in natural groups;
6. Application of research findings and approaches to the development of improved treatment and training procedures for retarded children; and
7. Extension and expansion of existing research training activities.

II. The Bureau of Child Research:

The Bureau of Child Research, established by the Kansas Leigslature in 1921, at the University of Kansas, was charged to work in a cooperative manner on research projects with hospitals, institutions, and other agencies of the state. The Bureau was not activated in its present form until 1955, when the Chancellor created it as an autonomous division of the University.

Since 1955, the Bureau of Child Research has functioned as an inter-disciplinary research center studying mentally retarded children. In addition to developing and maintaining such activities, the Bureau assists academic departments in related investigations and cooperates with state agencies and institutions wishing to develop research programs concerned with the needs of children.

A preschool and remedial assistance research program for children in Kansas City, Kansas is conducted by the Bureau of Child Research through its offices in the Children's Rehabilitation Unit at KUMC. This research program is made possible by grants from the Office of Economic Opportunity and the National Institute of Child Health and Human Development. The research program involves about 120 children from deprived homes. Project studies include:

(1) learning and development,
(2) longitudinal studies of growth and development of selected groups of retarded children,
(3) language development, and
(4) development of preschool setting.

A. Demonstration:

Demonstration projects conducted by the Bureau are:

1. "Demonstration of Therapy for Retardates with Communication Disorders," sponsored by the NIMH to provide advanced training in speech pathology and audiology for the mentally retarded.

2. "Demonstration of Intensive Training of Institutionalized Mentally Retarded Girls," a five-year, $475,000 project under auspices of the Division of Chronic Diseases, U.S. Public Health Service.

3. "Research Training Program in Communicative Disorders."

4. "Demonstration of Therapy for Retardates with Communication Disorders."

B. Training:

Training projects conducted by the Bureau are:

1. "Research Training in Communicative Disorders", under continuing grants from the National Institute of Neurological Diseases and Blindness.

2. "Research Training in Mental Retardation," NIMH - sponsored.

The joint effort of Parsons State Hospital and Training Center and the Bureau of Child Research at the University of Kansas has enabled Kansas to receive approximately $5 million by way of grants from Health, Education, and Rehabilitation agencies of the federal government.

III. University of Kansas Medical Center:

A. Research:

1. Specific Research Projects in the area of mental development at Children's Rehabilitation Unit include the following:

a. Perceptual Training for Social Behavior: A Pre-Vocational Unit for Retarded Youth.

b. A Study of Early Diagnosis and Clinical Education of Children with Learning Disabilities.

c. Program of Research in Communication Disorders of Mentally Retarded Children.

d. Exercise Abilities during Childhood.

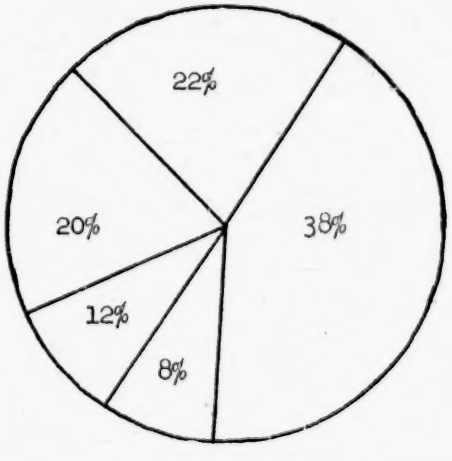
2. There are many research projects being conducted in several different departments at KUMC that relate to mental retardation, principally in the Departments of Anatomy, Biochemsitry, Pediatrics, Pharmacology, Psychiatry, Neurology (medicine), Neurophysiology (physiology), Obstetrics and Gynecology and Surgery. There are many short courses of a didactic nature and workshops conducted by various departments at the Medical School in conjunction with the Department of Postgraduate Medicine for graduate professional personnel in medicine, nursing and allied health professions in Kansas and the mid-west. Some such projects are:

1. "Development of Programs for Children with Specific Learning Disabilities"

2. "Early Diagnosis and Clinical Education of Children with Learning Disabilities"
3. "Role of Neonatal Hyperbilirubinemia in Production of Long-Term Neurological Deficits"
4. "Reproductive Rates among Female Relatives of Children with Idiopathic Mental Retardation"
5. "Long-Term Follow-up in Premature Infants with Respiratory Distress Syndrome"
6. "Subtle Long-Term Physical Deficits in Children, Both Premature and Term Births, with Neonatal Hyperbilirubinemia"
7. "Observations on Social Behavior of Retarded Children in a Laboratory Situation"

B. Training:

1. A large graduate training program is conducted at the Children's Rehabilitation Unit at KUMC in behalf of children who are mentally retarded and children who have a wide variety of learning disabilities of a chronic nature. During the Fiscal Year 1965-66 graduate training was provided for the following numbers of graduate students: medicine, 113; nursing, 100; special education, 196; hearing and speech, 62; occupational therapy, 18; physical therapy, 11; psychology, 2; social service, 2; dietetics, 6; total, 510. These training programs receive much financial assistance from the U.S. Department of Health, Education and Welfare via the U.S. Children's Bureau, the U.S. Office of Education and the Vocational Rehabilitation Administration and the NDEA Institute for Advanced Study. The pie chart below shows that 38% of the 510 students receiving training at the Children's Rehabilitation Unit were in the area of special education.



38% - Special Education

22% - Medical

20% - Nursing

12% - Hearing & Speech

8% - Other

2. Special post-doctoral programs in research training are conducted by the Department of Pediatrics and the Department of Special Education at KUMC.

3. The United Cerebral Palsy Foundation has provided the Department of Pediatrics $25,000 for Fiscal Year 1966-67 to improve teaching at KUMC in the area of cerebral palsy and related disorders. This award is renewable on an annual basis and is made in the form of a Dwight D. Eisenhower-United Cerebral Palsy Clinical Professorship to the Chairman of the Department of Pediatrics at KUMC, Dr. Herbert C. Miller.

4. The University of Kansas Medical Center Children's Rehabilitation Unit also conducted several "training programs" in the area of mental retardation:

   a. Training and demonstration in the areas of hearing, speech, pediatrics, and special education for the mentally retarded.

   b. Training in the problems of the emotionally disturbed child and orthopedically handicapped.

   c. Training graduate students, physicians, nurses and teachers in the area of mental retardation and other handicapped children.

   d. A selected demonstration for the vocational training of the mentally retarded youth in public high schools.

   e. Social-perceptual training for the vocational rehabilitation of mentally retarded adolescents.

IV. Parsons State Hospital and Training Center:

The major objectives of the Parsons Research Center are to investigate experimentally the factors which influence behavior and to apply the information gained from such experimentation to the management and training of retarded children.

A. Demonstration:

1. "Demonstrating Adaptive Behavior--A Psychiatric Problem" a five-year, $475,000 project established in 1964 in collaboration with the American Association on Mental Deficiency with financial support from NIMH, to define adaptive behavior as it relates to mental retardation and emotional disturbance, and to develop a reliable and valid technique for its measurement.

2. "Community Transition Program" established in 1964 as a three-year, $275,000 NIMH Hospital Improvement Project, and since extended to ten years with comparable funding on an annual basis. The program provides counseling and training, including sheltered workshop experience, to prepare the institution population for community life. Additional features of the program include consultant services by project staff to community agencies, and training of personnel for community facilities in the project's sheltered workshop.

3. "Expanded Training in Music Therapy".

B. Training:

1. State training funds ($49,496.36 in 1964 and $75,015.79 in 1965) continue to support basic inservice training for psychiatric aides and training for a limited number of college and university students and professional workers in psychology, special education, dietary services, recreation therapy, music therapy, and occupational therapy.

2. A five-year (1964-1969) $220,000 NIMH grant project in collaboration with the University of Kansas Department of Music and Music Therapy, provids ten traineeships annually for Kansas University graduate students to train one semester at Parsons State Hospital and Training Center.

3. "Extended Inservice Training of Patient Care Personnel," a five-year (1964-1969), $125,000 NIMH project providing training in the latest concepts in care and treatment of the mentally retarded designed for institution aides and graduate nurses.

4. "Summer Work Experience and Training" (SWEAT) sponsored by the Division of Chronic Diseases, PHS, to provide employment during summer, 1966, of college students preparing for careers in the field of mental retardation.

5. A summer, 1966, program providing work experience for special education teachers and students, carried out under provisions of Title I, Elementary and Secondary Education Act of 1965.

6. "Demonstration Project for Speech and Hearing Specialists," a program for advanced training in workshops, short courses, and individual traineeships, to provide experience in the field of speech pathology and audiology with the mentally retarded.

7. "A Project to Demonstrate that with Intensive Training Severely Retarded Girls can Function Adequately in the Home and Community Environments."

V. Kansas Neurological Institute:

A. Research:

1. Drug Study on Thozalinone
Sixty patients participated in this six-month study to establish possible benefits to a selected group (patients who were very passive or show little or no apparent interest in ward activities, school, or occupational therapy).

2. An Institutional Outbreak of Shigella Sonnei - Treatment of 36 Cases with Nalidixic
Of 36 cases (most of which had been treated with different antibiotics without results), 35 responded to Nalidixic Acid with good results. One case was resistant to the drug.

3. A Study of the Relationship of Socio-Economic Level to Various Patients Parameters in an Institution for the Mentally Retarded
Socio-economic level of 362 inpatients at Kansas Neurological Institute and 466 outpatients was determined to find the distribution on such parameters as measured intelligence, adaptive behavior, diagnostic classification, age, number of siblings, recommendation for hospital placement. In both populations a relationship was found between socio-economic level and: measured intelligence level, number of siblings, and patient age.

4. Influence of Visual and Ambulation Restrictions on the Stereotyped Behaviors of Severely and Profoundly Defective Males
This study investigated the influence of blindness and non-ambulation on stereotyped behaviors, self and environmental manipulations of severely and profoundly defective males (CA range 6-20). The sample included 32 subjects equally divided into ambulatory, blind nonambulatory, sighted ambulatory, and sighted nonambulatory groups. (To be published by A.A.M.D.)

5. Influence of Social Reinforcement upon Task Speed and Persistence: Methodological Consideration
This investigation was initiated to explore one area of Zigler's theoretical considerations and empirical findings of the effects of social reinforcement upon task persistence as operationally defined. Thirty-two moderately retarded subjects residing at KNI were administered a modification of the Zigler satiation task.

B. Demonstration:

1. Positive Student Nurse Attitude Change Towards the Mentally Retarded Following Patient Contact
Attitudinal tests were administered to 43 student nurses two weeks before the orientation. To one class, attitudes were tested after the first day of program; to the other, immediately following the two-day program. Greater positive attitudes were found when students were tested after working with the patients.

2. Survey of Treatment and Educational Facilities and Programs for Retardates with Accompanying Sensory Defects: Auditory and Visual Impairments
This project reports a survey of educational and social practices with residential retardates who are either visually or aurally impaired. Information relative to prevalence, education and training programs, teacher assignments and education, attendant training, program attributes and research activities was sought and tabulated.

3. The Relationship of the Field-Dependent and Field-Independent Cognitive Styles to Creative Test Performance
One hundred and thirty-eight undergraduate college males were administered individual and group measures of perceptual field-independent. Comparisons were made of the creative test performance of field-dependent and field-independent individuals.

4. Follow-up Study of 16 Children and Their Families Seen in the Child Study Unit of the Kansas Neurological Institute - 1962, 1963, and 1964.
Sixteen selected families (three from 1962, six from 1963, and seven from 1964) were studied to learn (1) the parents' conceptions and feelings regarding the evaluation in the Child Study Unit, (2) the extent to which the evaluation's recommendations could be implemented and were felt by the parents to be helpful and (3) the child's current situation.

5. Experimental Attempts to Reduce Stereotyping Among Blind Retardates
This study used stereotyped frequency as a dependent variable to measure the attention-holding properties of auditory, tactual, and auditory-tactual stimuli. Fifteen blind or severely visually impaired retardates are being included in the study.

6. Ward Program for Blind Children
Fifteen blind boys, ranging in age from about 5 to 21 (various mental levels), were placed together in July 1965, to institute more intensive and specific training in three major areas (1) daily living, (2) mobility, and (3) social rapport.

VI. Winfield State Hospital and Training Center:

Research:

A. "Study of Sebum Production in Castrate Males" - Dr. Strauss and Dr. Pochi of the Dermatology Department of Boston University Medical School are engaged in a study of the sebum production of castrate males at the institution. The project was begun in 1961. The doctors have made periodic visits to the hospital for further work and studies with our patients.

B. "Production of Urinary Gonadotrophins from Castrate Urine" - In 1958 a project was started in providing castrate urine for the production of urinary gonadotrophins. The actual study is done by the Snyder Research Foundation, Winfield, Kansas, and the Medical Center of the State University of New York.

C. "Statistical Study of Mortality and Survival" - The Downstate Medical Center of the State University of New York has been doing statistical research with regard to mortality and survival among the patients and former patients of the institution. The study has been in progress a number of years.

D. "Study of Spondylolisthesis" - A project initiated a year ago by the Wichita Clinic in regard to spondylolisthesis has not been completed yet.

E. "Use of Improved Feeding Techniques in Multi-Handicapped Children"- It is primarily designed to train children who are unable to feed themselves to benefit from an improved system of stimulating sensory reflexes in the oropharynx to faciltate swallowing. Later this is followed by finger eating and eventually self-dependence. During the period of this study, nutritional status will be assessed as to whether or not it will improve as the result of improved feeding.

VII. State Department of Public Instruction:

A cooperative research project funded from the U.S. Office of Education is entitled "Education of Educable Mentally Retarded in Sparsely Populated Rural Areas". This project was to develop and evaluate a program for educable mentally retarded children enrolled in the regular classroom in sparsely populated rural areas in Kansas. The three phases outlined for the study were: identification and selection of subjects; initiation of the classroom program; and evaluation of the classroom program.

A new research and demonstration grant from the U. S. Office of Education for a two-year study to implement research finding in curriculum development at the classroom level was granted beginning in 1966.

VIII. State Division of Vocational Rehabilitation:

"Emotional Correlates of Vocational Rehabilitation" - This project involved working with the urban renewal area in Topeka. Actual homes were visited and families were selected for further experimentation through intervention. Intervention was conducted by a psychiatrist, a psychologist, a social worker, and a vocational rehabilitation counselor. The attempt of this project was to see the results of intervention upon the poverty area in Topeka. Naturally, many of these individuals would fall within the range of being mentally retarded. (The Menninger Foundation conducted this research project, while the Board of Vocational Education arranged for the project to be funded with Vocational Rehabilitation funds.)

ACTIVITIES

There were numerous activities in which several state agencies were engaged during this planning period, ranging from inservice training to specific educational programs. Following is a description of the activities and services conducted by these agencies which include service to the mentally retarded:

I. University of Kansas Medical Center:

A. Children's Rehabilitation Unit. About 150 children, mostly from Johnson and Wyandotte Counties attend school regularly 11 months of the year at CRU. During Fiscal Year 1965-66, 150 other children received comprehensive evaluations, but were not admitted to the classes at CRU. Educational evaluations were given to an additional 112 children referred from various schools in that area. The psychology staff tested over 250 children. The social work staff carried 928 active cases and conducted 114 parent-guidance classes. The Hearing and Speech Department evaluated over 700 children. Approximately 1,900 physical therapy treatments and 2,100 occupational treatments were given to children at CRU.

B. Department of Pediatrics provided comprehensive evaluations on about 700 children who were mentally retarded or had disorders of cerebral function of any kind. Those with multiple handicaps, phenylketonuria, rubella syndrome, genetic defects are followed in the Birth Defects Center, located in the Outpatient Pediatric Clinic. Children are referred to the Department of Pediatrics and the Birth Defects Center from all over Kansas.

C. The Section on Neurology in the Department of Medicine and the Division of Child Psychiatry also evaluate children who are mentally retarded or have related disorders.

D. A new program initiated in 1964-1965 provided the Pediatric Outpatient Clinic with educational consultations from the staff in Special Education at the Children's Rehabilitation Unit for children who may be under-achieving in their local schools for any reason.

E. Arrangements have been completed during 1965 to provide intensive training in mental retardation for physicians in private practice.

F. A sequential comprehensive program for the preparation of professional personnel in special education has been developed for individuals who have contact with handicapped children. The program emphasizes three major areas as follows: 1) academic knowledge, 2) research experience, and 3) practical laboratory experience.

Post Graduate Courses and Workshops:

(1) "Voice Disorders"
(2) "Conference on Program Planning for Teachers' Preparation for Children with Mild Neurological Dysfunctioning"
(3) "The Nurse's Role in Screening of Communication Problems"
(4) "Hearing and Speech"
(5) "The Learning Environment: Implications for Special Education"

II. Board of Vocational Education:

The Board of Vocational Education through the Division of Vocational Rehabilitation has continued to maintain a high interest in providing services for the mentally retarded:

A. The Vocational Rehabilitation Unit of the Division of Vocational Rehabilitation has expanded its program in the past two years by adding two psychiatric social worker aides and providing a vocational rehabilitation counselor to work with the mentally retarded in the Wichita area.

B. Parsons State Hospital and Training Center is providing training films to the Vocational Rehabilitation Division for further assistance in training their employees to work with the mentally retarded.

III. Kansas State Department of Health:

The Kansas Department of Health, through the Division of Maternal and Child Health, has continually provided Kansas citizens with basic preventive programs in the area of mental retardation. The activity of this division is described in the following projects:

A. Three-day training institutes for public health nurses, school nurses, and hospital nurses, were sponsored by this Division and held at Parsons State Hospital and Training Center, Winfield State Hospital and Training Center, and Kansas Neurological Institute. The purpose of these institutes was to improve the nurse's understanding of the mentally retarded and how they can best assist in recognition, referral to needed resources, and supportive home visits to families having a retarded person.

B. The Department of Health gave financial and professional assistance to post-graduate students by planning and conducting three courses at the University of Kansas Medical Center, with attention given to mental retardation prevention and treatment.

C. Two-week health education workshops in 1964 and 1965 were held at Wichita University and Washburn University for school personnel--teachers, nurses, and administrators. They were financed and planned by the division. Both considered growth and development of children, with attention to the individual differences of children, and sections on mental retardation.

D. In the fall of 1965, six regional meetings were held by the staff for school nurses. One of the topics was the nurse's role in working with the retarded child in school.

E. During the spring and summer of 1964, there was a national outbreak of rubella. The Department of Health provided gamma globulin for injection after exposure and also coordinated referrals to the University of Kansas Medical Center for children suspected of being damaged by rubella.

F. The Department conducted a survey of child abuse in Kansas during 1962-63. In cooperation with the Kansas Medical Society, resulting from this survey, the Department sponsored a child abuse reporting law, which was passed during the 1965 legislature.

G. Consultation has been provided by the Department to local health department personnel engaged in family planning activities. This program received increasing impetus with the 1965 law providing funds for an educational program and for grant-in-aid funds to county health departments for clinic services.

H. Since 1963, the Division of Maternal and Child Health has conducted a hearing conservation project, screening school and preschool children throughout the state who have never previously had their hearing tested. A number of children who were thought to be retarded were found to have hearing impairment.

I. The Migrant Health Project grant was received from the U.S. Public Health Service in February of 1964 and continued during 1965, to provide health services to migrant families in western Kansas.

J. Implementation of the 1965 amendments to the school immunization law, which added measles as a requirement, has been another project of this department. The Vaccine Assistance Project was initiated by this department in 1964, with the target group being preschool children. Of particular importance in mental retardation prevention is the prevention of pertussis and measles diseases, potentially damaging to the central nervous system.

K. With an increasing incidence of syphilis and gonorrhea in teenage children, increased efforts have been given to this problem by the department, with particular attention to the unborn child.

L. A study of day care needs by income groups in Topeka was issued by the department in 1964. Since January 1964, seven day care centers in low income areas have been started and three are in the process of being developed. Consultation has also been provided to schools and community groups initiating "Head Start" programs. There has been a 30% increase in applications for a license from Day Care Centers for Retarded Children since January 1964.

M. Since January 1964, the Division of Health Education has added one or more copies of 20 new films on mental retardation. The pamphlet selection for the public and professional groups has also been expanded in the field of mental retardation. The program for providing mental retardation pocket materials as a cooperative activity of the Kansas Association for Retarded Children and the Department of Health, has been continued and expanded.

N. The first statewide perinatal casualty report for 1960 and 1961 was issued in 1964 and has been widely distributed. This study included an analysis of 3,000 perinatal casualties compared with 100,000 total births, with many charts, tables, and discussions of pinpointing high risk groups and medical conditions which may result in mortality and morbidity, such as mental retardation.

O. A referral program for public health nursing visits to families with children being discharged from mental retardation institutions was conducted by this department.

IV. State Department of Public Instruction:

The State Department of Public Instruction through its Division of Special Education has maintained a high priority for the need of expanding classes for the mentally retarded.

A. Since 1963, there has been an increase of 1,500 children being served in both educable and trainable public school classes. With the passage of Public Law 89-10, increased requests of funds for trainable classes are expected.

B. In the past several years, this department has developed classes for the mentally retarded in rural communities with several school districts developing cocperative programs.

C. The State Division of Special Education and the State Division of Vocational Rehabilitation have developed tentative standards for cooperative special education and rehabilitation programs in Kansas senior high schools.

V. State Board of Social Welfare:

A. The State Board of Social Welfare, through the Division of Institutional Management, has maintained its concern for problems of mental retardation by:

1. Administering the statewide planning for mental retardation under Public Law 88-156.
2. Overall updating of services in the institutions caring for the mentally retarded. (These hospitals have one of the better patient-personnel ratio's in the nation.)
3. Encouraging each hospital to engage in direct service projects such as:

   a. Extending their training facilities for student nurses, ministers, and other professions in training;
   b. Reaching out to communities throughout the state in establishing local programs such as sheltered workshops, parent counseling, and other services; and
   c. Disseminating their expert knowledge through speeches, papers, seminars, workshops, institution and division periodicals, etc.

B. The Division of Social Welfare under the State Board of Social Welfare has continued to encourage activities at the community level in providing services for the mentally retarded through the county departments of social welfare. The following activities have been conducted:

1. They have been available for counseling with retarded persons and their parents.
2. They have continued to provide essential social history information so state institutions could more adequately meet the needs of the retarded person.
3. They have recruited and stimulated the growth and development of boarding homes, day care homes, adult boarding homes, and nursing homes that serve the retarded in their own communities. They also have been engaged in the licensing of these facilities.
4. To an extent, the county welfare departments, supervised by the Division of Social Welfare, have been acting as points of referral in that they have been the one authority within the community who knew what facilities were available for the care and treatment of retarded individuals and their families throughout the state.

5. They have also assisted in financing day care facilities for handicapped children.
6. They have made available educational leave stipends for graduate training in social work.
7. They are conducting a state-wide survey of the need of day care services for all children.

LEGISLATIVE ENACTMENTS

One of the major reflections of public attitudes and citizens interest is the translation of needed changes and improvements into public law. A number of legislative actions of particular relevance for the retarded took place in the 1963 and 1965 legislative sessions.

1. K.S.A. 79-1409, 72-6785, 72-6764: These three bills concern the school unification laws and affect mental retardation by:

   a. enlarging enrollments, which make better groupings of retarded possible within their districts;
   b. offer more services, which include personnel working in areas of identification and parental counseling in areas of exceptional children; and
   c. permit schools to employ personnel offering ancillary services, which are a necessary part of the special education program for the mentally retarded (speech correction, vision, etc.) (79-143 is a 1963 law)

2. K.S.A. 65-180: Provides for the establishment of an intensive statewide educational program by the State Board of Health concerning the disease phenylketonuria, and statewide screening and laboratory tests. This bill provides for the establishment of a registry of cases of PKU and provides for the necessary treatment product by diagnosed cases.

3. K.S.A. 38-716: Concerning battered children, this act makes a mandatory reporting by medical personnel, social workers, registered nurses, and institutions of certain physical abuse of children. This law provides for immunity from liability for anyone participating without malice in the making of such a report.

4. K.S.A. 75-3329: This act authorized the State Department of Social Welfare to place certain children in licensed private children's homes. It provides for the cost of the placement to be incurred by the Board if the child's parents or guardians are not able to pay this cost themselves and are not eligible for assistance under existing Kansas statutes.

5. K.S.A. 72-5381: This act provides that any pupil entering school for the first time shall be required to certify that he has received a test for tuberculosis and is freed from a contagious form of this disease, and that he has received immunization against poliomyelitis, smallpox, diphtheria, measles, pertussis, and tetanus.

6. K.S.A. 59-2006: This act is concerned with payment for care of patients in the state mental hospitals and hospitals for the mentally retarded: Patient or estate, $9 per day; responsible relative (spouses, parents and children), $12 per week; and recovery.

7. K.S.A. 72-5301: This act is concerned with the education of blind, deaf, hearing and sight handicapped children. It is the intent of this act to provide for a procedure to place these handicapped children (ages five to twenty-one) in an environment for their education which is best suited to the individual needs of each such child and the provisions of this act shall be liberally construed to accomplish this purpose.

8. K.S.A. 59-3001: This act makes a distinction between guardianship and conservator. The guardian shall be any person appointed by court to exercise control over the person of an incapacitated person. The conservator shall be any person who has been appointed by court to exercise control over the estate of any person. This law provides more flexibility in selecting someone to care for the needs of the mentally retarded person who is in need of supervision in relation to his severity of impairment.

9. K.S.A. 39-709: Eligibility requirements of applicants for or recipients of assistance. The state agency shall, in determining eligibility to receive assistance of any kind by an adult incapacitated person or disabled child who became incapacitated or disabled prior to his 21st birthday, waive all or any portion of the resources and income of the parents of said child if, in considering such resources or income, undue hardship will be forced upon the parents.

10. K.S.A. 39-1001: Prescribes the powers and duties of the State Board of Social Welfare in providing aid to local community organizations for the development, maintenance, improvement, or expansion of day care programs for the mentally retarded and other handicapped individuals. It also established a "Day Care Advisory Committee."

11. K.S.A. 65-5a01: This law allows retarded to receive orthopedic services from the Crippled Children's Commission, by amending the previous law to delete "of sound mind."

12. K.S.A. 23-501: This act relates to the public health and welfare; directing the State Board of Health to establish and maintain family centers to furnish and disseminate information concerning the means and methods of planned parenthood; and prescribing the duties of the state and county boards of social welfare and county health departments in connection with this act.

13. K.S.A. 72-7001: An act relating to schools; providing for state financial aid to elementary and high schools; creating a state school foundation fund and county school foundation fund and providing for the distribution of said funds under the formulas stated in the act; creating a school budget review board and defining its powers and duties; authorizing tax levies; prescribing the duties of certain state, county and school officials.

14. K.S.A. 76-149 to 155: Certain laws, not currently utilized, allowing for sterilization in certain state institutions, were repealed.

(For a more thorough account of what the Kansas laws entail, consult the State of Kansas Session Laws, 1963 through 1965 or the Kansas Statutes Annotated, and supplements.)

Some federal laws also passed during this period which affect our mental retardation planning in Kansas are:

1. Public Law 88-164: Title I of this law provided for funds for the construction of three types of facilities for the mentally retarded. The following construction programs are administered by the United States Public Health Service:

   a. Research centers for the development of new knowledge for preventing and combating mental retardation.
   b. University-affiliated facilities for the mentally retarded to provide for training of physicians and other professional personnel vitally needed to work with the mentally retarded.
   c. Construction of community facilities for the mentally retarded which begun in Fiscal Year 1965. Facilities constructed under this legislation may include a variety of services: diagnosis, treatment, education and training or care of the mentally retarded.

   Title III of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 has already demonstrated the widespread interest and need for research and training in the area of the handicapped. Centers established specifically for research and training in the field would permit more systematic program development and use of professional manpower.

2. Public Law 89-10: The Elementary and Secondary Education Act of 1965 will given an enormous impetus to developing educational services for the retarded. Title I authorizes a three-year effort to encourage and support the creation, expansion, or improvement of special programs. Title III of this act opens up opportunities to the mentally retarded for instruction in science, languages, music, and the arts, and regular, easy access to museums, laboratories, art galleries and theatres.

3. Public Law 89-333: To amend the Vocational Rehabilitation Act to assist in providing more flexibility in the financing and administration of state rehabilitation programs, and to assist in the construction, establishment, expansion, and improvement of services, facilities, and workshops. It includes a provision for vocational rehabilitation services for a period up to eighteen months to determine eligibility in difficult cases of mental retardation.

4. Public Law 88-156: To amend the Social Security Act to assist states and communities in preventing and combating mental retardation through expansion and improvement of the maternal and child health and crippled children's programs, through provision of prenatal, maternity, and infant care for

individuals with conditions associated with childbearing which may lead to mental retardation, and through planning for comprehensive action to combat mental retardation, and for other purposes. (1963)

5. Public Law 89-97: This law provides for a two-year extension of P.L. 88-157 and is for the purpose of planning and implementing mental retardation services throughout the nation. This law authorizes grants totaling $2,750,000 under Section 1701 of the Social Security Act.

As can be seen from the preceding pages, there have been numerous activities, a variety of research projects, and very important legislation affecting the mentally retarded citizens of our state. Although there has been a great amount of interest in the problems of mental retardation, program development has been primarily centered at the institutional and university level. Kansas must now develop ways in which knowledge can flow from the institutions to the community and, in turn, knowledge of the needs of the community flow back to the institutions. There is a definite need for expansion of community services, as can well be seen from the recommendations in the following chapter, to develop this needed institutional-community continuum of service.

CHAPTER V

RECOMMENDED PATTERNS OF SERVICE

Expansion of existing services and resources, as described in Chapter III, will not begin to adequately combat the problem of mental retardation as it exists in Kansas today. What is needed is a broader pattern of unified state action extending from the local through the state level of involvement. However, to accomplish this, it is necessary to utilize existing resources as an integral part in the more comprehensive pattern of services. Coordinated with the established programs, new services should be developed to meet the entire needs of the retarded.

Following is a description of the areas needing immediate and special attention by the citizens of Kansas, along with a list of recommendations to assist in meeting these areas of deficiency. These recommendations are the result of an attempt by over two hundred Kansas citizens and professionals to find feasible solutions to problems in mental retardation as they now exist.

STATE ORGANIZATION

Citizens and professionals who studied this problem most frequently expressed a need for a state-level agency, organization, or commission on mental retardation to coordinate and unify efforts of the various state agencies whose programs either serve or can be of potential service to the retarded. In response to this great concern to coordinate and actively pursue an effective program for the retarded, the following specific recommendations were proposed:

I. That a Governor's "State Inter-Agency Council on Mental Retardation," consisting of 12 members appointed by the Governor, be statutorily created.

II. That responsible representatives composing this 12-member State Inter-Agency Council should come from the following agencies:

1. Labor
2. Education
3. Institutional Management
4. Welfare
5. Vocational Rehabilitation
6. Health
7. Board of Regents
8. Attorney General's Office
9. Crippled Children's Commission
10. University of Kansas Medical Center
11. Penal Institutions
12. Vocational Education

III. That the functions of the proposed State Inter-Agency Council should be:

1. To report to the Governor, the Legislature and various other state agencies and organizations working with the mentally retarded on the types of programs currently serving the mentally retarded and possible improvements needed.

2. To conduct bi-monthly meetings; keep minutes of these meetings and send them to the Governor and interested state agencies.

IV. That a Governor's "State Advisory Council on Mental Retardation," consisting of 12 members, also be statutorily created. This Council should meet with the proposed State Inter-Agency Council periodically, as well as separately.

V. That representatives on this 12-member State Advisory Council be lay citizens, such as members of Kansas Association for Retarded Children, Kansas Association for Mental Health, professional organizations and other interested citizens concerned with mental retardation.

VI. That an "Executive Secretary" should be appointed by the Governor and that this position be statutorily created. That the Executive Secretary be a full-time, paid employee with experience in the field of mental retardation. This individual should have professional training in a related profession. His primary role should be that of coordinator of the proposed State Inter-Agency Council on Mental Retardation and secretary of the State Advisory Council on Mental Retardation.

VII. That "Special Advisory Councils" be appointed by the State Inter-Agency Council when deemed necessary. The duties of the Special Advisory Councils should be to assist the State Inter-Agency Council in further study of specific areas in mental retardation.

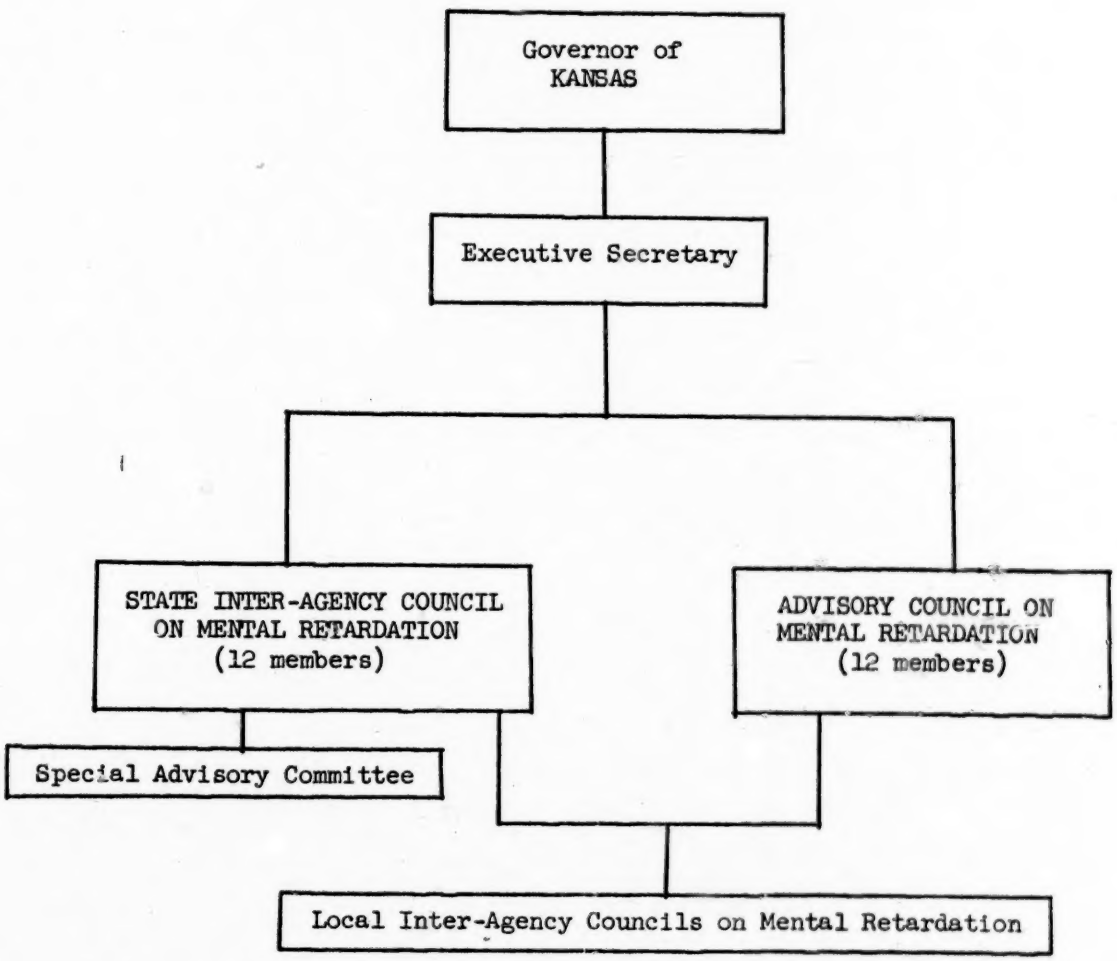
VIII. That members of the State Inter-Agency Council on Mental Retardation develop similar geographic regions in which their respective field representatives operate. At this time, there are no such common regional boundaries in which the above named state department members represented on the State Inter-Agency Council can function together.

(See Chart #1 on the following page for the "Administrative Structure of Proposed Councils on Mental Retardation.")

Chart #1

ADMINISTRATIVE STRUCTURE OF PROPOSED

COUNCILS ON MENTAL RETARDATION



ORGANIZATION OF COMMUNITY SERVICES

Kansans are becoming aware of their responsibilities in developing necessary programs to more satisfactorily work with the mentally retarded. For the proposed State Inter-Agency Council to function most effectively, the following steps should be taken to insure the organization of services as a parallel function of efforts at all levels. Thus, the following was recommended:

I. That heads of agencies represented on the State Inter-Agency Council on Mental Retardation direct members of their field staffs to meet together with interested citizens and professionals on a regional or local basis in helping to establish ongoing local inter-agency councils concerned with mental retardation problems. Field staff members should help define local needs, help form plans to meet these needs, assist in more effective collaboration, and provide a framework for communication from the local to the state level and vice versa.

II. That Local Inter-Agency Councils on Mental Retardation be formed on a community, county, district, or regional basis and may include representative groups such as the following:

1. County Welfare Departments
2. Public Health Departments
3. Public Schools
4. Area Vocational Schools
5. Vocational Rehabilitation
6. State Employment Offices
7. Juvenile Court
8. Staff of State Hospitals
9. Local Recreation Commissioners
10. Local Association for Retarded Children
11. Ministerial Alliance
12. Association for Mental Health
13. Local Sheltered Workshop
14. Community Mental Health Center
15. Local Hospital
16. Family and Children's Service Agencies
17. Medical Representatives

III. That these local inter-agency councils on mental retardation be encouraged to take the following steps for action:

(1) Identify all existing resources.
(2) Make recommendations for
    a. Improvements and extensions of existing services
    b. Additionally needed new services.
(3) Make recommendations for needed new services to be supported through county and local financing.
(4) Develop inter-agency cooperation.

FIXED POINT OF REFERRAL

A most vital aspects in the program of services for the mentally retarded is the establishment of a "fixed point of referral." There is a need for a community level and state level fixed point of referral which would be designated as being responsible for knowledge of the various services available for assisting the mentally retarded and his family. This point of referral should have information about availability or scarcity of resources necessary to provide a continuum of services. The fixed point of referral could act as coordinator for the family's referral to and use of available services. The following is hereby recommended:

I. That each individual community, district, or region should designate an individual, group or agency as a fixed point of referral. This responsibility could be established in a mental health center, public health department, social welfare department, local association for retarded children, school, state hospitals and training centers for retarded children, and so forth.

II. That the point of referral at the state level be the Executive Secretary of the State Inter-Agency Council. This person would be engaged in assisting with coordinating services at the local level and with supplying necessary information to the local "points of referral." He could assist in referring any individual or group seeking information concerning mental retardation to the proper state agencies or local resources.

DIAGNOSIS AND EVALUATION

There is a great need for additional diagnostic and evaluative services of various levels, degrees, and gradations throughout the state of Kansas. There is a need for more general types of evaluation which can be provided by personnel located nearer the local communities. It is apparent that not every retarded child in the school system needs a complete comprehensive diagnosis and evaluation. It is also obvious that not every retarded child exhibiting emotional problems needs to be seen at one of the five comprehensive diagnostic centers in Kansas, but could possibly receive this service from a mental health center.

Another important factor is that the five comprehensive diagnostic and evaluation centers are located in the eastern half of the state, thereby placing some hardship on citizens in western Kansas. Considering these facts, it is hereby recommended:

I. That schools expand their psychology and social work staffs so they may provide fact-finding diagnosis and evaluation services for all school-age children needing special education.

II. That 25 Community Mental Health Centers be developed. As of this date, there are 21 such centers located throughout the state. The centers should be encouraged to provide services for the retarded as an integral part of their programs.

III. That in areas where Comprehensive Mental Health-Mental Retardation Facilities develop, such centers provide for the retarded the services of a psychiatrist, psychologist, social worker, pediatrician, neurologist, public health nurse, speech therapist, audiologist, and education and rehabilitation consultants, in order to be qualified to use the joint title "Comprehensive Mental Health-Mental Retardation Facility."

IV. That diagnostic programs in any resource where diagnosis is represented as being "comprehensive" shall include:

a. A complete medical assessment of all physical and neurological factors involved.
b. An evaluation of measured intelligence and adaptive capacity.
c. A diagnostic assessment of emotional factors involved.
d. A diagnostic assessment of associated social-family factors.
e. A translation of the diagnostic findings into recommendations and referrals appropriate for the life-long social management of the retarded. This information should be conveyed to the parents in terms which are understandable to them.

V. That Parsons State Hospital and Training Center, Winfield State Hospital and Training Center, and Larned State Hospital be provided additional funds to employ staff on a full-time basis to administer outpatient diagnostic and evaluative services for the retarded child and his family.

VI. That the Child Study Unit, the comprehensive evaluation center located at the Kansas Neurological Institute, be expanded so it may provide more than the present three to six evaluations per week.

VII. That the University of Kansas Medical Center develop a specialized clinic to provide diagnosis and evaluation of the brain injured, emotionally disturbed, and mentally retarded adults and children. The present practice of having separate services for each handicap on a referral basis is complicated, making evaluation services cumbersome and somewhat inefficient.

VIII. That an additional comprehensive evaluation service be developed in the western part of Kansas wherever feasible, with regard to availability of necessary staffing and equipment.

IX. That to facilitate the development of a variety of diagnostic resources, the state should make funds available for assisting in the expansion and development of such facilities.

PARENTAL COUNSELING

Parental understanding and counseling, of the nature and extent needed, must come from a variety of sources. Parents of mentally retarded children generally turn to their physicians and/or ministers before approaching agencies with their problems. It is therefore recommended:

I. That the State Department of Health, Kansas Medical Society, the University of Kansas Medical Center, and other involved state agencies, be encouraged to expand programs to inform physicians of current knowledge in the area of mental retardation and of the steps needed in parental counseling, including referral to appropriate resources.

II. That more workshops and/or training programs be established for ministers, public welfare workers, public health nurses, school personnel, and other related professionals who work directly with the mentally retarded. These specific individuals have the primary role of "listening" and making proper referrals. They are, in essence, the central therapeutic agent within each of their respective communities. The workshops should provide current information and methods of counseling as it relates to the field of mental retardation. A "continuum of services" should be the main theme of these workshops.

III. That the training programs mentioned in the above recommendation be the responsibility of state educational institutions in cooperation with state hospitals, community mental health centers, and related state agencies.

IV. That community mental health centers, family service agencies, and schools include parental counseling with the mentally retarded in their programs, and that designated members of their staff receive special training in this area.

V. That the specialized agencies, such as community mental health centers, etc., extend their services to also provide consultation to the groups named in recommendation number two.

HOME TRAINING

Closely related to the problem of providing adequate parental counseling is home training assistance. Not being equipped with specific knowledge and ability necessary to train their retarded offspring effectively, parents may need a community agent to help teach such skills and provide assistance in a manner that would help

insure a more stable and healthy home environment. Because of this widespread need for personnel to help parents of retarded children begin and maintain a healthy home life conducive to maximum development, the following is recommended:

I. That the State Department of Health expand and improve its program in conjunction with county health nursing services to include:

   a. Availability of county public health nurses to work closely with other agencies in providing home training and child management services to the families of retarded children.

   b. Availability of county public health nursing services to work closely with other agencies in training personnel to assist and perform the above home training services.

II. That the State Department of Social Welfare expand and improve its program of homemaker services to include all families of retarded children who need such services.

III. That local inter-agency councils on mental retardation help designate what professionals and lay citizens are to assist with parent training of the retarded child in the home. These local councils should first seek assistance from the local county welfare department, public health nurse, school personnel, home economic agents, mental health personnel, and other such knowledgeable persons concerned with mental retardation.

SPECIAL EDUCATION SERVICES

The mentally retarded, because of their primary deifict in intellectual functioning, are unable to profit adequately from the general public school programs. Therefore, educational programs for the retarded must be directed toward the more specific handicaps, needs, abilities and ultimate possibilities of the retarded.

Also, the formal educational aspects, as well as the routine socialization experiences involved in classroom training for the mentally retarded, are major determining factors in the eventual adjustment of these individuals. It is quite obvious that these experiences should be provided for the retarded in, or as close as possible, to the community in which they will be expected to live. In an effort to broaden and strengthen special education services in Kansas so that, without exception, these valuable experiences will be readily available to all retarded able to profit from them, the following recommendations are proposed:

I. That provisions be made for immediate expansion of public school classes for the educable and trainable retarded in all local public schools. The following procedures should be pursued in this expansion:

a. Legislation should be passed making it mandatory for public schools to provide appropriate instructional and budgetary plans to include programs for both the educable and trainable mentally retarded.

b. The Division of Special Education in the State Department of Public Instruction should be strengthened by additional staff and increased appropriations so it may more effectively develop and support the necessary classroom services for trainable and educable mentally retarded from preschool through senior high. This division should be encouraged to continue developing comprehensive services such as psychology, speech, social work, etc. in the area of special education.

c. To insure full-range educational services from preschool through senior high, the six-year minimum age should be stricken and a three-year extension should be added to the 21-year age limit, when needed. Involvement of the Special Education Division into the preschool area of services should be determined by inter-agency deliberations. Joint planning by the Division of Vocational Rehabilitation, Division of Adult Education, and other related programs under the Department of Vocational Education should also be pursued for conducting education during the transition period and the post-school period of training.

II. That the Kansas State Division of Vocational Rehabilitation should become a more complemented part of the state's special education program and that special education curriculum should be tailored to include vocational training. This curriculum should also include provision for services of public health officials, social workers, and other similar disciplines so that a comprehensive education for practical living can be achieved before the student goes into an independent living arrangement.

III. That the number of school psychologists and social workers be expanded so that a diagnosis and evaluation can be obtained for every child to determine those needing special education programs. These persons should also act as a liaison between the school and diagnostic clinics within the community or area. These individuals should be qualified as to minimal professional education standards in social work and psychology.

IV. That full consideration be given to establishment of cooperative program arrangements among school districts, particularly for the trainable retarded as a means of providing special education classes in rural areas of the state. If this cooperative program is to become a reality, a study is needed of the transportation problems involved. A possible solution of the transportation problem would be the establishment of boarding home facilities. The State Departments of Education, Social Welfare, Health, and Vocational Rehabilitation could concur in the organization of these boarding home services.

V. That local school districts with large numbers of special education classes employ a supervisor of mental retardation. In rural areas this individual could be employed on a cooperative basis among districts.

VI. That existing coordinators of research for all educational programs be utilized by special education personnel for developing research and demonstration programs.

VII. That programs in curriculum development and implementation be organized at both state and local levels for trainable and educable classrooms. (Refer to Chapter IV, page 30.)

VIII. Studies should also be made to determine the feasibility of establishing material and resource centers for a continuous inservice training program.

IX. That the Institute for Research in the Education of Exceptional Children continue an evaluation of existing teacher-training programs and teacher-certification requirements in the area of special education.

X. That when a school district plans for building expansion or improvement consideration be given to present and future special education needs.

XI. That special education should be removed from the 104% limitation of the school foundation formula.

XII. That the State Colleges and Universities be encouraged to expand their teacher-training programs in special education.

TRANSITIONAL ASPECTS OF SPECIAL EDUCATION AND VOCATIONAL REHABILITATION SERVICES

A number of vocational services are needed in order to insure that the retarded may be able to make the transition to sheltered or gainful employment after completion of special education programs. To effect a coordinated transiton from special education to vocational rehabilitation programs that would rule out any possibility of a gap between services at this stage of a retardate's adjustment, the following recommendations are proposed:

I. That special education programs provide academic and social living classes for students up to 21 years of age and the vocational rehabilitation services, focusing on job training, be available to those individuals who are capable of such programs. Vocational rehabilitation services should work with students of reasonable age and/or social development even though they cannot place them into a job until they are at least 16 years of age.

II. That vocational rehabilitation counselors be made available to:

1. Work with the retarded student and his family over a period of time in exploring and planning vocational goals;

2. Work with the local school in establishing work sample tryouts to gain more extensive knowledge of students' latent abilities and interests;

3. Consult with the school administration and its teaching staff when providing rehabilitative services; and

4. Maintain the necessary ratio of approximately one counselor per 60 students over the next ten years.

III. That the Employment Security Division of the State Department of Labor coordinate its services with special education and vocational rehabilitation to form a more complete transitional program for the retarded. This department should assist in finding employment opportunities after education and vocational rehabilitation training have been completed.

IV. That this transitional program be further coordinated with the Office of Economic Opportunity for adult educational services during the adult years of the retardate's life.

SHELTERED WORKSHOP SERVICES

For the retarded individual who may not be able to pass directly from the school system to some sort of vocational training or productive work situation, the experience which a sheltered workshop provides should be made available. This particular type of facility is defined as "a place where any manufacture or handiwork is carried on, and which is operated for the primary purpose of providing gainful employment to the severely handicapped 1) as an interim step in the rehabilitation process for those who cannot be readily absorbed in the competitive labor market; or 2) during such time as employment opportunities for them in the competitive labor market do not exist."[14] In order to help make sheltered workshop services more regionally accessible across the state, the following steps are recommended for action:

[14] Federal Register, Department of Health, Education and Welfare, Vocational Rehabilitation Administration. Vol. 31, No. 9 (Washington, 1966), p. 500.

I. That collaboration between vocational rehabilitation and special education services in local school systems be expanded to include development of a program for establishment of corollary sheltered workshop facilities to provide prevocational training and/or sheltered employment.

II. That these facilities, located throughout the state, should be available for recreation and leisure-time activities while not being used for work training purposes. These facilities should become activity centers whose programs should be coordinated by the special education and vocational rehabilitation departments.

III. That the State Inter-Agency Council on Mental Retardation make provision to insure that these sheltered workshop and/or educational-activity facilities receive fair and equitable state reimbursement for services that correspond to education and/or vocational rehabilitation services.

IV. That these facilities become part of comprehensive local plans so that they may become eligible for mental health, education, vocational rehabilitation, and mental retardation construction funds, and that the development of multiple financing be encouraged as a foundation for matching funds.

V. That the school for the blind and the school for the deaf expand their programs to include rehabilitative services for blind and deaf mentally retarded individuals. In support of this recommendation, it is known that some of the workers trained to work with the deaf and the blind have skills that make them excellent teachers of the mentally retarded.

VI. That applications be made for construction funds for residential facilities in conjunction with sheltered workshop facilities from the Division of Vocational Rehabilitation.

VOCATIONAL REHABILITATION UNIT

The Vocational Rehabilitation Unit (VRU) is a 90-bed residential facility which provides comprehensive vocational rehabilitation services to the mentally retarded. The goal of this program is to prepare mentally retarded persons of employable age for remunerative employment. The VRU is operated by the State Board for Vocational Education, Division of Vocational Rehabilitation, and is located in ten buildings on the grounds of the Kansas Neurological Institute in Topeka. Even though VRU provides adequate facilities and training for the retarded, there are still problems which must be met. To more fully provide the necessary expansion of services and a much broader scope for the type of training now available at VRU, it is hereby recommended:

I. That more VRU staff be employed to be stationed in the field so that follow-up service, help with job finding, and other vocational rehabilitation assistance will be more readily available on the local level for students who progress through the VRU program to placements in communities throughout the state.

II. That VRU be allowed flexibility in adding to or modifying its evaluation and training areas to keep pace with changing labor market conditions. This will include authorization to engage in appropriate sub-contract operations for industries and businesses.

III. That the use of VRU as a research, demonstration, and training facility be expanded.

STATE OPERATED RESIDENTIAL FACILITIES

Institutionalization of a mentally retarded individual, when and if it does occur, should be quite thoroughly thought out in advance. The primary role of a state operated residential facility should be to provide services and training to mentally retarded persons when such services cannot readily be provided in their own community. In order to achieve an institutional program which would be consistent with a community centered emphasis, the following is recommended:

I. That the Division of Institutional Management be charged with conducting the research necessary to identify those trends for institutional services which are applicable to Kansas. These needs should be determined with a view toward establishing the types of services needed in Kansas residential facilities, to determine what programs or facilities will be needed to provide services for all ages and all degrees of disability.

II. That this research be aimed at an examination of the categories of patients

(a) presently being served in the institutions,

(b) presently on the waiting lists for the institutions and

(c) in (a) and (b) above which could be better served by community programs and services.

III. That this research be conducted to determine the relative need for (a) specialized residential facilities and (b) general comprehensive facilities on a regional or community basis.

IV. That the Executive Secretary of the State Inter-Agency Council on Mental Retardation work in close cooperation with the director of admissions for institutions (a)to effect a mutual understanding of the resources that exist throughout the state as alternatives to institutional placement, and (b) to recommend placements with an understanding of an overall system of services.

V. That the field representatives of various state departments which provide services for the mentally retarded be further trained to act as "points of referral" to assist and inform the retardate and his family of residential services available. Also, that at least 1/3 of their time be devoted to the area of mental retardation--as is being done by some of the public health nurses in Kansas.

VI. That training and research activities be strengthened in the state operated residential facilities for the mentally retarded.

VII. That trends for state operated residential services needed in Kansas be identified and planned. This would include defining the roles of the present state operated residential facilities and the roles and need for smaller regional-general units where residential care would be involved.

OTHER RESIDENTIAL FACILITIES

It is highly desirable to provide residential care for the retarded whenever possible with local facilities, physically separate from the state's residential facilities. Many citizens have expressed a need for these different types of facilities as alternatives to institutional care. To extend the availability of adequate residential facilities to the mentally retarded, and provide for an array of alternatives to residential placement, the following is recommended:

I. That residential facilities be established on a local or regional basis. These residential facilities are to be supported by public and/or private funds. (i.e., the Lakemary Center residential facility for the trainable retarded at Paola, specialized nursing homes for the severely handicapped, and residential facilities in conjunction with sheltered workshops.)

II. That the State Inter-Agency Council on Mental Retardation assist in developing standards for specialized residential facilities for use by the young adult and adult retarded. That these standards give attention to:

a. the necessary supervision of personnel engaged in the care and management of these facilities;

b. the adequate care and treatment of the retarded residents;

c. regular and routine consultation visits by social workers, institutional workers, and other mental health and public health professionals;

d. suitable housing, furnishings, adequate food and personal services;

e. thorough and adequate selection and placement processes used in assigning residents to various facilities; and

f. the use of specialists such as physicians, nurses, therapists, and nutritionists, as consultants in the operation of these facilities.

III. That the local inter-agency councils on mental retardation be charged with an active survey and assist the social agencies with recruitment of foster homes and families for those retarded who can profit by this service. This is necessary to provide:

a. boarding facilities for those who need to attend cooperative special education classes located away from their homes;

b. group living facilities for retarded individuals engaged in either vocational training or work placements;

c. half-way houses for those retarded individuals discharged from state residential facilities who can better take advantage of existing community services; and

d. increased remuneration for these services. A complete study should be made to insure for a realistic pay formula.

IV. That all these facilities, for both the child and adult retarded, be required to provide some type of activity program in the home and/or within the community to qualify for a license.

V. That support be given for establishing facilities within local communities to care for severely and profoundly bed-fast mentally retarded persons. These facilities should be publicly financed and licensed.

VI. That, since the law treats the mentally retarded adults as children, insurance carriers and companies should, by law, retain these handicapped individuals over age of 21, in the family insurance policy. Presently, the law does state that parents are responsible for their handicapped child after he reaches age 21, but insurance companies do not include coverage for adult retardates under family rates.

VII. That applications be made for innovative grants from the Division of Special Education and the Division of Vocational Rehabilitation to develop programs to meet the needs of the multi-handicapped children.

GROUP-DAY CARE CENTERS

A "Group-day Care Center" is defined as a facility providing care for five or more children over three years of age, for part or all of a day, away from the home of the parent or legal guardian. It includes full day-group care, nursery schools, play groups, centers giving emphasis to special programming for children, kindergartens not accredited by the State Department of Public Instruction, and other establishments offering care to groups of children for part or all day services. Since these centers are exceedingly valuable as preventative and habilitative facilities, it is recommended:

I. That the State Department of Social Welfare through the Division of Child Welfare Services provide funds to stimulate and establish a wider variety of day care programs for handicapped children.

   a. This Division become primarily responsible for establishing a network of such services.

   b. This Division gather necessary data and information to insure an orderly expanded development of such a system of services; and

   c. This Division continue to increase its budget for stimulating development of local day care services.

II. That the local inter-agency councils:

   a. encourage development of these centers and arrange for suitable multiple financing to meet matching fund requirements;

   b. help recruit and train volunteers and paid assistants to staff and operate these facilities;

   c. assure for necessary consultation and other assistance to sustain their operations;

   d. encourage inclusion of mildly and moderately retarded children in the classes of present ongoing nursery schools and preschool centers; and

   e. in high risk areas, particularly where deprivation is widespread, insure that adequate day care and nursery school services are available for all children and that these services include the program requirements (a through e) as listed in The Report of The Committee on Preschool Life Stages, Task Force on Life Stages, p. 34.

III. That the training of staff for preschool and day care centers in deprived areas and in centers for retarded preschool children be included in educational curricula, nursery school educational training, and child development programs of colleges and universities in the state.

IV. That the State Inter-Agency Council on Mental Retardation work with the State Department of Health and the Department of Social Welfare to support and encourage a state program for establishment of preschool enrichment centers in rural areas and areas with a concentration of lower socio-economic groups and aid local groups attempting to deal with these problems.

PREVENTION

Since mental retardation results not from one but from many disorders, it calls upon knowledge from almost every branch of science, including the biological, medical, social, and behavioral. To achieve the broadly based program needed to prevent the occurrence of mental retardation, it is recommended:

I. That the Kansas State Department of Health expand its program of public awareness and education necessary for wider application of preventative measures, and that this include:

   a. Education of the public in regard to the need for continuous health supervision, basic nutrition, preventative health care, poison control, and accident prevention;

   b. Continuing education of professionals, such as physicians and nurses, along with allied professional groups, on ways and means of implementing application of preventative measures; and

   c. Control of communicable diseases such as measles, rubella, syphilis, etc., all of which may result in mental retardation.

II. That the State Inter-Agency Council on Mental Retardation explore the possibilities of expanding genetic information centers with the State Department of Health and the University of Kansas Medical Center. Also, that they include discussions of the possibility of establishing a central registry of genetic conditions.

III. That, to help provide control of prenatal and post-natal factors which can lead to retardation, the following steps should be taken:

   a. Adequate public health nursing services should be developed in each county following the ratio of one nurse to every 5,000 population, so that there will be enough nurses to make home visits to families, when necessary, both before and after the birth of "high-risk" infants;

b. Maternal health clinics should be developed through cooperation of the county health departments and the State Department of Health in population centers which have a high incidence of perinatal mortality and morbidity. These should be developed in close coordination and assocation with the proposed mental retardation centers;

c. Routine screening for phenylketonuria, as required by law, and other inborn errors of metabolism and blood group incompatabilities should be extended along with appropriate medical management of these infants; and

d. Expansion of the perinatal mortality or morbidity studies, as a joint project of the Department of Health and the Kansas Medical Society.

IV. That the State of Kansas commit itself to the prevention and remediation of widespread adverse living conditions, and that the State Inter-Agency Council on Mental Retardation be responsible for identifying "high-risk" areas and advising for needed area redevelopment and urban renewal programs.

V. That special account should be given to the preventative significance of nursery school and day care centers for preschool children and that the local inter-agency councils should:

a. Promote establishment of these facilities in deprived neighborhoods and rural areas and

b. Coordinate operation of these facilities with the maternal health clinics proposed in (b) of recommendation III of this section.

VI. That family planning information be made available to all state and private agencies serving the mentally retarded.

VII. That family life education be provided in the public schools.

VIII. That family planning centers, provided for by law in 1965, be established throughout the state.

IX. That information concerning voluntary sterilization be disseminated to parents of retarded children and that procedures for its use be established in accordance with medical advice. With the repeal of the sterilization law, K.S.A. 79-9957, sterilization is possible on medical recommendation.

X. That study and review of current marriage laws be conducted. This study should explore the feasibility of providing premarital counseling, physical examination, laboratory tests, and genetic counseling before issuance of the marriage license.

XI. That, if family related courts are created in Kansas, they become concerned with premarital counseling and assume professional responsibility in the same manner that they would with divorce action and marital counseling.

XII. That legislation be enacted for justifiable abortion. This should be under the auspices of a licensed physician if he believes there is substantial risk that continuance of the pregnancy would present a threat to the life of the mother; that the child would be born with grave physical or mental defects; the pregnancy resulted from rape by force or its equivalent; or from incest. Also, that three physicians, one of whom may be the person performing the abortion, have certified in writing, their belief in justifying the circumstances and have filed such certificate prior to the abortion in the licensed hospital where it was to be performed or in such another place as may be designated by law.

XIII. That the State of Kansas provide the necessary appropriations for continued research toward the area of prevention in mental retardation.

RESEARCH

Research in mental retardation is vitally needed to acquire a better understanding of the ways and means by which this condition can be prevented, and to know how it can better be treated once it does occur. Further basic research into the causes of mental retardation and factors underlying treatment is necessary, along with applied research into specific ways of better serving the retarded through evaluation of existing programs. To promote a research program that will lead to productive results in prevention, program evaluation and continued planning in Kansas, the following is recommended:

I. That the State of Kansas provide the appropriations necessary for research directed toward prevention and ongoing evaluation of training and treatment programs for the mentally retarded. This recommendation is based on the fact that the average cost to the state of Kansas is $11.16 per day to care for one retarded person in a state institution. Since the average stay is 12.7 years per person, it costs approximately $51,730 to care for each retarded individual during his period of stay in a state institution. With 2,300 mentally retarded patients currently being served, this indicates there is great need for expanded research to devise means in which prevention and community services can be developed. The legislature has already begun to realize the need for the State to participate in research by appropriating $50,000 to the State Board of Social Welfare, Division of Institutional Management, for Fiscal Year 1966. There needs to be more.

II. That financing of research programs in other states be investigated. State financing such as the following may be examples for study:

a. Illinois--the payments for institutional care of children and relatives go into a research fund.

b. Missouri--each year the Governor sets aside a certain amount of money to match federal funds research.

III. That needed research be conducted to evaluate effectiveness of existing and newly implemented programs in mental retardation throughout the state, so that revision and continued improvement of services may be an ongoing process.

IV. That the State Inter-Agency Council on Mental Retardation support the now-existing "Research Center for Mental Retardation and Related Aspects of Human Development," (Located at Parsons State Hospital and Training Center, University of Kansas Medical Center and University of Kansas at Lawrence) to further study the pediatric and child development research activities as part of an overall program for prevention. That support also be given to this research facility to further study the possible expansion into <u>all</u> aspects of etiology in mental retardation.

V. That the State Inter-Agency Council on Mental Retardation establish a permanent committee on research which will work with the council to provide a forum for the exchange of information.

This committee should be composed of the Executive Secretary and representatives from: The Menninger Foundation, Kansas Research Foundation, Vocational Rehabilitation, Special Education, Research Center for Mental Retardation and Related Aspects of Human Development, Division of Institutional Management, plus members from other interested agencies who conduct research in mental retardation.

VI. That the State Inter-Agency Council on Mental Retardation explore the feasibility of developing an informational storage and retrieval center to bring together and organize data and information from various related agencies, groups, individuals and other sources.

VII. That the State Inter-Agency Council on Mental Retardation analyze both the residential and waiting lists of populations currently on the roles of the state residential facilities for the retarded. This could be considered as part of the research and planning necessary for further development of community facilities.

VIII. That the Kansas Research Foundation take an active role in statewide mental retardation research activities.

IX. That all major research agencies and programs in the state be provided with an opportunity to utilize, on a cooperative basis, existing facilities, such as closed circuit television, data-phones, and central computors.

X. That other communities throughout the state conduct individual planning projects such as the one recently conducted by the Community Studies, Inc. for the Greater Kansas City area. This type of approach would enable communities to systematically plan for meeting the needs of their mentally retarded citizens.

PUBLIC AWARENESS

Since a program of public awareness in mental retardation cannot be assigned as the province of any one agency or special group, an attempt must be made by all relevant groups and agencies to inform the public-at-large of the vital matters relating to mental retardation. Public awareness should provide a foundation for the community support necessary for the success of mental retardation programs. To favorably promote attitudes and interests of the public, the following is recommended:

I. That each of the Local Inter-Agency Councils on Mental Retardation designate a responsible person to carry out public awareness and education programs in their area.

II. That the Kansas Association for Retarded Children provide workshops each year, in cooperation with the Division of Institutional Management, for training of local public education chairmen.

III. That dissemination of information should include youth groups, (Scouts, 4-H, etc.) P.T.A.'s, religious groups, women's groups, service and fraternal organizations and public and private schools.

IV. That, where possible, community mental health centers and/or mental retardation centers have resource material and information available for use in county activities.

V. That the following organizations and agencies be contacted for distribution of their publications and films as public education materials:

a. Kansas Association for Retarded Children--"Tracks"
b. President's Committee on Employment of the Handicapped--"Tips and Trends in Employment of the Mentally Retarded"

c. National Association for Retarded Children--"Children Limited"
d. State Department of Health
e. Kennedy Foundation
f. United States Department of Health, Education and Welfare
g. Four State Residential Facilities for the Mentally Retarded--"KanSan," "Parsonian," "Scope," "Broadcaster"
h. Division of Institutional Management--"Scope," INFO, "Taproots"

VI. That an effective film on mental retardation in Kansas be produced by television technicians and information specialists. Also, that television managers should be encouraged to schedule not only this film but also be encouraged to do special programs in local activities in the field of mental retardation.

VII. That legislators should be informed on a year-round basis as to what is happening in the state concerning mental retardation. And, that this could best be accomplished at the local level where person to person contacts could be made by the public awareness and education program coordinators in the various areas of the state.

VIII. That the Executive Secretary of the State Inter-Agency Council on Mental Retardation have on his staff an education and information specialist for the state's mental retardation program. Also, that this specialist provide for a continuous public awareness program on mental retardation that would be an ongoing, well-organized program throughout the state.

IX. That a "Resource Guide" or document be developed on a state-wide basis and that the local inter-agency councils on mental retardation should develop specific resource documents in their own areas.

X. That the Division of Health Education Services continue to expand its total library in order that it can continue to effectively provide educational services for the citizens of Kansas.

XI. That the Division of Institutional Management's Community Mental Health Services continue to disseminate appropriate information.

XII. That the Kansas State Department of Health expand its program of public awareness and education necessary for wider application of preventative measures, and that this include:

a. Education of the public in regard to the need for continuous health supervision, basic nutrition, preventative health care, poison control, and accident prevention;

b. Continuing education of professionals, such as physicians and nurses, along with allied professional groups, on ways and means of implementing application of preventative measures; and

c. Control of communicable diseases such as measles, rubella, syphilis, etc., all of which may result in mental retardation.

MANPOWER

Throughout the planning conducted by the 18 planning task forces, the recurrent theme of manpower shortage arose. It is well documented that no matter what the interest or intent of local communities or state agencies have in attempting to provide services for the mentally retarded, they generally cannot find trained personnel. It is therefore recommended:

I. That the Coordinator of the Center for Research in Mental Retardation and Related Aspects of Human Development Project, as mentioned in the section on Research, apply for a grant under Public Law 88-164, Part B, Title I, for the establishment of a university-related facility. This project would provide clinical-training for many of the professional fields currently providing services for the mentally retarded. The purpose in seeking this addition to the existing research center is to make appropriate use of the university resources, including personnel, and thereby creating a better means of training personnel needed throughout the state. This facility financed through federal and state funds, would also create physical plant additions to each of the three existing centers for research in mental retardation, thereby providing additional diagnostic and training units.

II. That the above clinical-training facility provide for use of other state residential facilities as part of the training program.

III. That the Institute for Research on Exceptional Children, an advisory group to the State Board of Regents, begin planning for the expansion of training programs at the various state universities and colleges. They should also look into the feasibility of using junior colleges and the state residential facilities for the mentally retarded in developing long-range plans.

IV. That residential facilities serving the mentally retarded provide training programs for non-professionals and professionals entering the field of service to the mentally retarded and that these programs be in the form of workshops, seminars and inservice training.

V. That each state agency involved in care, treatment, and/or training of the mentally retarded provide inservice training programs for its staff at least once a year to keep abreast of current knowledge and practice.

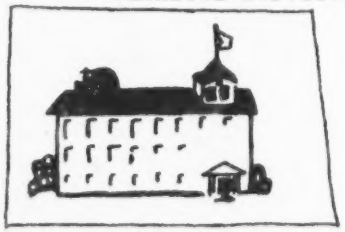
VI. That salaries of personnel in our various state departments, universities and colleges be increased to meet competition for professional personnel from other states and private industries.

VII. That a very thorough study be undertaken to examine the reasons for professional personnel leaving the state and to further find solutions to this problem.

Diagnostic and Clinical Services

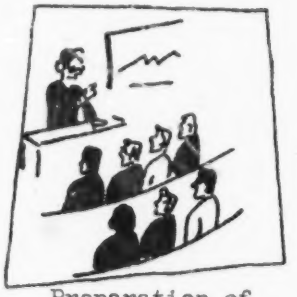
Research

Day Care, Recreation



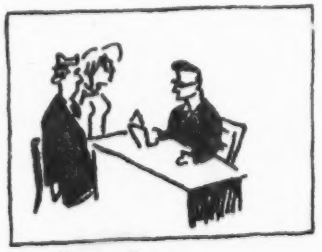
Care in Residential Institutions

NEEDED AREAS OF ACTION



Preparation of Professional Personnel

Special Education



Home Care
Parent Guidance

Maternal and Infant Care

Vocational Rehabilitation

Mental Retardation: A National Plan for a National Problem, The President's Panel on Mental Retardation; Chart Book: U.S. Department of Health, Education, and Welfare, p. 41.

CHAPTER VI

PLAN FOR ACTION

A program for mental retardation in Kansas began when the first State Asylum for Idiotic and Imbecilic Youth was established at Lawrence in 1881. Very little attention was given to actual program development; primary emphasis was on providing custodial care. After 1950, Kansas began developing comprehensive services and programs through various state and private agencies. Although facilities and programs at the state level have greatly improved, a majority of the retarded in Kansas do not have access to these programs. With approximately 66,000 mentally retarded individuals in the state, current state-wide programs are only able to serve approximately 10,000. These statistics indicate that there are many unfortunate individuals in Kansas who could benefit from some help.

For instance, there is the retarded person living in a small community who tries to play with each succeeding generation of younger children, or one who sits quietly and resentfully at the back of a schoolroom never having a program for his educational level. Instead of these individuals being isolated from the community, they need a chance to develop into useful human beings just as any other citizen. There are many areas of services in mental retardation which, if investigated and expanded, could provide the necessary assistance to help the retarded become useful citizens. These include expansion and development of resources, prevention, research, and many other areas of concern. All need immediate and special attention by Kansans.

State level government must continue to provide leadership in the field of mental retardation. To enhance this leadership ability, a recommendation has been made that an "Executive Secretary" be appointed by the Governor to be a coordinator of services in mental retardation. This individual would act as secretary for a "State Inter-Agency Council on Mental Retardation." The Council would coordinate their programs consisting of 12 state-wide agencies offering services to the mentally retarded. By coordinating their efforts, all agencies would be better equipped to combat mental retardation in Kansas.

Also working with the "Executive Secretary" and the "State Inter-Agency Council" would be an "Advisory Council on Mental Retardation." This Advisory Council would be composed of 12 lay citizens, advising the Governor and State Inter-Agency Council on matters relating to mental retardation.

The State of Kansas must continue to take responsibility for establishing manpower training programs in mental retardation in state colleges, universities, and institutions. This responsibility could be accomplished, in part, with the establishment of a university-related facility for clinical training in various professional fields.

The State must also continue to concentrate on prevention of mental retardation. Although Kansas has been a leader in many areas, such as mandatory legislation on immunization for measles, and testing for phenylketonuria, there are additional areas for prevention that must be expanded and supported. The area of prevention is one in which the local communities can and must give concrete support (i.e., expansion of local health services, public education).

It is quite evident that all problems encountered by the mentally retarded cannot be dealt with solely from the state level. Local communities play a major role in combating problems of mentally retarded citizens. Because of this responsibility, it has been proposed that "Local Inter-Agency Councils on Mental Retardation" be formed on a community, county, regional, or district basis. In forming such councils, all citizens interested in and working with mental retardation should be informed and invited to take an active role in these councils. Each council's representation could be as follows:

1. County Welfare Departments
2. Public Health Departments
3. School Administration
4. Vocational Schools
5. Vocational Rehabilitation
6. State Employment Offices
7. Juvenile Court
8. State Hospitals
9. Local Recreation
10. Local Association for Retarded Children
11. Ministerial Alliance
12. Association for Mental Health
13. Local Sheltered Workshop
14. Community Mental Health Center
15. Local Hospital
16. Family and Children's Service Agencies
17. Medical Representatives
18. Citizens
19. Civic and Social Organizations
20. O.E.O. Programs
21. City, County, and State Government
22. Private Agencies

The duties of such a local inter-agency council would be to: consider the facilities now existing, and determine what services should be extended to better serve the retarded and his family; research and study what specific problems exist and thereby give support to establishing new services; establish a fixed-point-of-referral which would coordinate referrals for services; disseminate information about mental retardation; make applications for federal and state funds for establishing needed facilities; compile a directory of existing local resources; coordinate and evaluate existing and newly established services; establish a finance committee for fund-raising endeavors and to investigate all private, state, and local funds for developing mental retardation services; act as a public awareness and education organization openly talking about mental retardation in an attempt to inform more persons; propose and support any legislation deemed necessary; and promote recruitment and training of people to work in the field of mental retardation.

For example, this council, upon study, may determine that a day-care center is what is first needed in its specific area. Through investigation, the council would learn that this center provides retarded children of preschool age with emotional and intellectual stimulation during their formative years and that this helps prepare them for later assimilation into regular school classes. In some cases, day-care centers can provide help for those children too severely retarded to benefit from any type of special education or vocational training programs. All day-care facilities should be established through coordination with the State

Departments of Social Welfare and Health. To help provide this type of facility for the mentally retarded, it has been recommended that funds be made available by the Division of Child Welfare for stimulation and establishment of a wider variety of day-care programs, and that this Division become primarily responsible for establishing a network of such services as part of its function. This council may also support the establishment of Head Start Programs, as these programs perform similar functions as Day-Care Centers.

If special education classes for the educable and trainable retarded are found to be the most vitally needed service by the local council, it should then work closely with local school administrators who will, in turn, work with the State Department of Public Instruction--Division of Special Education--to develop appropriate diagnostic services for identifying those needing services and initiating programs. To help provide this vitally needed community service, it has been recommended that legislation be passed making it mandatory for public schools to provide classes for both educable and trainable mentally retarded. But, until this is done, the community, or "local inter-agency council," must ask for assistance and encourage school boards and administrators to establish these classes.

If, through community investigation, a sheltered workshop is found to be the service most needed, the local council may request assistance and consultation from the State Department of Vocational Education, Division of Vocational Rehabilitation, or Community Mental Health Services. With training in a sheltered workshop, some mentally retarded can gain vocational skills and experience which would enable them to use their skills productively. Hopefully, some could go on to advanced training that would lead to employment in the community. There are many routine, non-skilled jobs which a trained retardate may handle more efficiently than can a person of normal intelligence.

A sheltered workshop facility might also be used as an activity center for the retarded. Due to the retarded person's dire need for recreation, using work facilities also as activity centers would begin to meet a few of the recreational needs of the mentally retarded.

In planning and establishing these and other facilities for the retarded, support should also be given to expanding personnel and programs in local health and welfare agencies. This support is necessary if existing services are to be extended to all families of retarded children.

In addition to establishing these services in the local communities, there is great need for more research into prevention and control of mental retardation. Research is costly, and matching funds for federal research grants are not always available when they are needed. To assist in expanding research in mental retardation, it has been recommended that further expansion and allocation of state funds be provided.

In establishing any one service, the question of financing will arise. Both on the local and state level, there should be an exploration of all potential private, state and local funds for use in developing mental retardation services. This type of exploration will enable local councils to better plan for development of facilities necessary to serve the mentally retarded.

Kansas has come a long way in a short time toward meeting the problem of mental retardation, but there is an even longer way to go. The growing waiting list of parents seeking help for their children is constant proof that existing institutions, no matter how adequate a job they are doing, can never meet the total needs of all the mentally retarded. The retarded need help--help through development of community resources for care and training in the community where they live.

A long road ahead has now been opened to the citizens of Kansas by completion of the initial planning phase. The communities, institutions, state and private agencies, and local, state, and federal government must now accept their roles so that a "continuum of services," will be available to the retarded, and so a strong preventative program can be carried out.

Congressman Fogerty put it well when he stated: "Time does not stand still for the retarded while those who control his destiny quibble. The job is to define the needs of the retarded, to request the demand that these needs be met. The passage of time will only make more desperate the needs of the retarded that are not being met today."

APPENDIX A

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